
Social Justice, Health Disparities, and Culture in the Care of the Elderly

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This paper addresses two interconnected concepts — health disparities and social justice — as they pertain to screening, diagnosis of disease, and health care access among minority elders in the American society. Health disparities are defined as differences in treatment provided to members of different racial or ethnic groups that are not justified by the underlying health conditions or treatment preferences of patients.¹ Disparities currently exist in many aspects of American health care. For example, when compared to whites, the infant mortality rate is higher for African Americans; health insurance coverage is lower for Latinos and African Americans; and ethnic minorities experience poorer care and survival rates for HIV, even after controlling for other confounding factors including income, insurance, health status, and severity of disease.² Among older Americans, health status varies by race, income, and gender. Older minority Americans have consistently been shown to have worse health than whites of the same age group across measures of disease, disability, and self-assessed health.³ When compared to whites, elderly Latinos have higher rates of diabetes and disabilities,⁴ and older African Americans have more chronic conditions.⁵

According to Barry Levy and Victor Sidel (2005), social justice encompasses two distinct ideas based on the underlying themes of justice, fairness, and equity.⁶ The first is that individuals should not be denied of economic, socio-cultural, political, civil, or human rights based on the perception of their inferiority by those with more power or influence. This can

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be exhibited through forms of stigmatization or stereotyping particular groups. The second idea is that society — as a collective — must act to ensure the conditions under which people can be healthy, in the form of policies and actions that affect societal conditions. The idea of social justice can be applied directly to all areas of health care, particularly access, diagnosis, and provision.

In the context of health disparities, social justice refers to the minimization of social and economic conditions that adversely affect the health of individuals and communities. Several factors related to social injustice may lead to increased rates of disease, injury, disability, and death. These factors include poverty, inadequate education, lack of health insurance coverage, and limited availability of medical care.⁷ Advocates of social justice have long established the need to provide comprehensive health care services that would aid every individual,⁸ regardless of income, geographic location, and racial identification. This mission is even more urgent for America’s elderly minority population, as reflected by the nation’s primary policies in health care. The Healthy People Report of 2010 identifies eliminating health disparities and improving quality and years of life as the two central goals of the nation’s health care agenda. These issues remain of critical importance in the Healthy People 2020 initiative. Research has revealed that inequity in the provision of medical needs is more common among older African Americans, older women, as well as those with incomes below the poverty line.⁹ The implications of this from a social justice perspective are numerous, as the injustices of health care are reflected through the inability of the most vulnerable minority elders to access quality and equitable care when they need it the most.

The interaction of health disparities, justice, and cultural interpretation of disease is presented as a complex problem that researchers and providers must unravel in order to reduce inequalities in health care, while being aware of cultural differences and promoting equality for all older Americans. With this concern in mind, in this paper, we use a case study on Alzheimer’s disease as an example of the profound disparities and social injustices faced by older minority Americans. We discuss what we call “the conundrum of health disparities” — the intricate and difficult prob-

Figure 1
“The Conundrum of Health Disparities”



lem of distinguishing between disparities in diagnosis and treatment based on need — and the role that cultural perception and normalization of disease (in this instance Alzheimer’s disease) plays in racial and ethnic minorities being less likely than whites to receive and utilize health care services. The conundrum takes into account, as noted in Figure 1, the relationship between disparities, cultural beliefs and perceptions, and lack of social justice in differences in diagnoses, access to care, and screening.

Case Study: Alzheimer’s Disease

One of the greatest challenges facing America today is providing health care to a growing and increasingly diverse aging population. By 2030, the segment of the U.S. population aged 65 years and older is expected to double, and the estimated 71 million older Americans will make up approximately 20 percent of the total population. Additionally, the proportion of older Americans belonging to racial and ethnic minority groups is expected to increase significantly. Age is a key risk factor for developing one of the most feared, misunderstood, and costly diseases of later life: Alzheimer’s disease. Recent figures indicate that an estimated 5.3 million Americans currently have Alzheimer’s disease, including about 10 percent of people over 65 years of age and nearly 50 percent of people over 85.¹¹ The number of people with Alzheimer’s disease is expected to increase yearly and is projected to affect 11-16 million older adults by 2050.¹² These figures underscore the scale of the public health problem facing the nation¹³ and the need for policymakers, health care providers, community service organizations, and family caregivers to understand how to improve screening measures, diagnosis, and access to care for those with this disease.

Alzheimer's disease is a progressive brain disease that destroys brain cells, causing problems with memory, thinking, and behavior, which affects the ability to work, socialize, and care for oneself. As the disease progresses, Alzheimer's patients increasingly need assistance with basic activities of daily living (ADLs), such as eating and dressing as well as functions that enable them to live independently, including shopping and managing money (i.e., instrumental activities of daily living [IADLs]). In the final stages of the disease, patients require 24-hour care. Alzheimer's disease is ultimately fatal. In 2006, it was the sixth leading cause of all deaths in the United States and the fifth leading cause of death among Americans above the age of 65.¹⁴

Older minority populations, particularly African Americans, are at greatest risk for developing

ate health care, normalization of illness, and delay in seeking proper diagnoses and care are also important factors that must be addressed in combating disparities in Alzheimer's disease and ensuring social justice for the most vulnerable groups of Americans.

Expanding upon culturally correlated factors that perpetuate inequity in Alzheimer's disease, we focus on four salient disparities and social justice issues in the management of Alzheimer's disease: (1) differences in perception about the causes of the disease; (2) disparities in screening to validate the existence of the disease; (3) disparities in timing of diagnosis of the disease; and (4) disparities in access to care to treat the disease. Although each of these issues is distinct, they are interconnected in creating and perpetuating disparities among older minority Americans and impacting health outcomes.

Expanding upon culturally correlated factors that perpetuate inequity in Alzheimer's disease, we focus on four salient disparities and social justice issues in the management of Alzheimer's disease: (1) differences in perception about the causes of the disease; (2) disparities in screening to validate the existence of the disease; (3) disparities in timing of diagnosis of the disease; and (4) disparities in access to care to treat the disease. Although each of these issues is distinct, they are interconnected in creating and perpetuating disparities among older minority Americans and impacting health outcomes.

Alzheimer's disease.¹⁵ This is in part because older African Americans are more likely to suffer from high blood pressure and high cholesterol than their white peers. Emerging evidence suggests that both of these conditions are major risk factors for Alzheimer's; having one of them doubles the risk of developing the disease and having both conditions nearly quadruples the risk.¹⁶ Paradoxically, despite being more at risk for Alzheimer's disease, older African Americans are diagnosed much later in the disease process than older whites and, as a result, face significantly higher dementia-related morbidity and health care costs.¹⁷

Minority elderly populations face severe barriers to social justice as it pertains to Alzheimer's disease screening, diagnosis, and treatment. These barriers include structural (living in an inequitable geographical/regional location), economic (poverty), and social/clinical (health illiteracy).¹⁸ As a result, these barriers often limit access to care and discriminate against older minority populations,¹⁹ thereby exacerbating inequities in Alzheimer's disease care. Cultural differences in interpretation of disease, lack of culturally-appropri-

Differences in Perception

Perception is the process, act, or faculty of perceiving — attaining awareness or understanding. It is the ability to identify, interpret, and attach meaning. Thus, perceptions of dementia — particularly myths and fallacies — negatively affect early access, diagnosis, and treatment of Alzheimer's disease. Peggye Dilworth-Anderson and Brent Gibson (2002) reported that cultural values and beliefs among different ethnic groups affect the meanings they assign to dementia,²⁰ and that these cultural meanings help to create barriers to seeking assistance outside the family system. Other researchers have found that when comparing the cultural interpretations of dementia by diverse communities, having dementia was perceived by some Latinos as being "crazy" or having "bad blood."²¹ In cultures where religious beliefs involve spirit possession, these beliefs also shape dementia perceptions. In these cultures, faith healing and prayer are used to ward off evil spirits that are believed to be responsible for the illness.²² Additionally, Asian families often have stigmatizing perspectives and meanings attached

to dementia.²³ For example, Korean American immigrants have been shown to have strong stigma about Alzheimer's, interpret the disease as a form of insanity, and consider memory loss and Alzheimer's disease as a part of the aging process.²⁴ Further, Korean Americans who were less acculturated and less exposed to Alzheimer's were likely to have poorer knowledge about the disease.²⁵ Under their cultural influence and stigma, Korean American families may recognize signs of Alzheimer's in their relatives, but may not want to seek outside help to avoid community awareness and stigmatization.²⁶

J. Scott Roberts and colleagues (2003) found that race is more powerful than family or caregiving history in explaining differences in illness perception. They found that African Americans showed less awareness of facts regarding Alzheimer's disease than did whites.²⁷ African Americans also reported having a fewer number of sources of information about Alzheimer's disease than did whites, and perceived Alzheimer's disease as less of a threat than did whites. All of the families associated old age with memory loss, and viewed symptoms as role performance. Unlike any other group, whites believed that females were more likely to experience memory loss. White families also saw dementia-associated behavior as similar to previous behavior, and were more likely to recognize a problem when the care recipient violated conventional gender roles. The authors found that white families were more likely than African American families to recognize behaviors as a sign of serious illness without a culminating event. African American families were more likely to identify with dementia when it consumed an individual's personality, while American Indians were more likely to view dementia as a role performance problem. The same study found that African Americans viewed Alzheimer's disease symptoms as a normal part of aging.²⁸

Findings from an ongoing qualitative study of 25 families (10 African American, 10 white, 5 American Indian; N=80) entitled "Perceiving and Giving Meaning to Dementia" conducted by Peggy Dilworth-Anderson, show that comparable to findings by Roberts et al. (2003), family caregivers construct dementia in four different ways: contextually, situationally, culturally, and personally. *Contextually*, caregivers question behavior and performance based on where they live (i.e., behaviors are less prescriptive in rural versus metropolitan areas, which allow for differences in perception about dementia). *Situationally*, caregivers express that the behaviors of the older family member with dementia were dependent on their environment and surrounding circumstances (i.e., when people expect little from elders, they can exhibit a wide range

of behaviors that were acceptable, even dementia). *Culturally*, caregivers think about dementia according to the beliefs and values within their culture (i.e., when cultural values allow people to be different and a range of behavioral differences are acceptable, dementing behaviors are not "non-normal"). *Personally*, caregivers express concerns about themselves and their older family members within acceptable cultural beliefs and values (i.e., acceptance and concern are both culturally and situationally determined). Dilworth-Anderson's study also reinforces the idea that African Americans associate Alzheimer's disease symptoms and behaviors as a normal part of aging, thereby delaying the diagnosis and treatment of the disease.

Disparities in Screening

Screening is important in the management of Alzheimer's disease in order to identify those individuals at greatest risk at an early stage of disease development. According to the Alzheimer's Association, ethnic and cultural bias in current screening and assessment tools is well documented.²⁹ Joan Stephenson and colleagues (2001) reported that bias in screening tests have been shown to disproportionately misclassify as many as 42 percent of black Americans without dementia as being demented versus only 6 percent of whites.³⁰ These differences reflect an overestimation of Alzheimer's disease and dementia diagnoses among blacks and a bias in the current data and literature. As a result, African Americans who are evaluated have a much higher rate of false-positive results. At the same time, there is substantial evidence of underreporting of dementia among African Americans. Similarly, Jennifer Manly and David Espino (2004) reported that discrepancies in the diagnosis of dementia among minority elders might be due to detection bias on the part of clinicians or might result from the use of inaccurate or culturally insensitive testing methods.³¹ These testing methods may artificially decrease the number of minorities diagnosed with the disease, thus delaying diagnosis and leaving many individuals without needed services during the critical initial stages of the disease.

Disparities in Diagnosis

Early diagnosis of Alzheimer's disease allows medical professionals to intervene and treat a number of symptoms as soon as individuals begin to show signs of Alzheimer's disease. Evelyn Teng (2002) reported that key factors in misdiagnosis of dementia include language barriers and interpretation and low levels of education among elders.³² Ladsen Hinton and colleagues (2005) recognized that illness attribution and perceptions play an important role in shaping decisions to seek help or adhere to treatment recommen-

dations.³³ These factors directly influence how both patients and families communicate with providers and adequately access resources. Patricia Clark and colleagues (2005) reported that individuals can delay physician consultation by as much as seven years due to normalization (i.e., the view that aging brings about dementia and senility) of dementia in diverse communities.³⁴ These researchers also highlight the lack of physician contact as a major issue of concern for African American families caring for an individual with Alzheimer's disease, from the onset of the disease throughout its progression. Lastly, among Medicare beneficiaries, African Americans are diagnosed dis-

cans, when compared to whites, reported lower use of a range of information sources about dementia (e.g., media, reading materials, health care professionals, friends, lay organizations, and relatives).³⁹ Overall, the literature on service needs and access to care for older adults with dementia is important in helping to develop policies that support caregivers in their care management, including finding and using information and assistive services. However, the literature is inadequate in explaining the critical question of *why* caregivers, especially minorities, underutilize services that are needed and may be within reach.

Overall, the literature on service needs and access to care for older adults with dementia is important in helping to develop policies that support caregivers in their care management, including finding and using information and assistive services. However, the literature is inadequate in explaining the critical question of *why* caregivers, especially minorities, underutilize services that are needed and may be within reach.

proportionately more than whites.³⁵ These racial differences are not only prevalent in dementia diagnosis, but also in the physical effects of dementia and the use and costs of health services.

Disparities in Access to Care

Access to health care, according to the Institute of Medicine, is the timely use of personal health services to achieve the best possible outcomes and is a prerequisite to obtaining quality care.³⁶ Access to quality health care is crucial to the proper treatment and care of patients diagnosed with Alzheimer's disease. Jennifer Mackenzie and colleagues (2005) suggest that more research is needed to provide evidence-based information and research to assist health care professionals to work more effectively with people with dementia from diverse ethnic and cultural groups.³⁷ This can come in the form of cultural competency training and materials for all health care professions, particularly for those who regularly interact with minority communities. Cheryl Ho et al. (2000) found that African American and white dementia caregivers had similar *types* of unmet service needs (e.g., social services, followed by medical services and mental health services), but African Americans expressed a greater *degree* of need in comparison to white caregivers in all service categories except medical services.³⁸ Roberts et al. (2003) found that African Ameri-

Conclusion

This paper provides a discussion on health disparities and issues related to social justice in the care of older adults from minority groups, with an emphasis on Alzheimer's disease. While a number of conclusions could be drawn from what is discussed, we conclude that one major focus deserves attention: the conundrum of health disparities and social justice. The conundrum encourages asking several key questions: Can we claim a "disparity" if individuals do not access health care due to their cultural beliefs and values? How do we bridge the connection between what individuals believe in and what is socially just in the provision of health care? We propose that such questions must be answered and addressed by researchers, educators, health care providers, and policymakers to help eliminate health disparities and create a more socially just health care system and society.

Helping to eliminate health disparities and creating a more socially just society will also require that we not only speak about cultural competency, but take concrete steps toward this process. Several steps are proposed. First, knowing and understanding the culture of a group provides a conceptual and methodological "blueprint" to follow. Ward Goodenough's work on culture informs the elements of this blueprint and can help direct our thinking about the role culture should play in providing care to our most vulnerable groups in society. Goodenough (1981) defines culture as a set

of shared symbols, beliefs, and customs that shape individual and group behavior and provide guidelines for speaking, doing, interpreting, and evaluating one's actions and reactions in life.⁴⁰ The concept of "cultural frame" provides further insight into how individual characteristics (e.g., gender, age, etc.) and experiences can influence cultural beliefs and values. Cultural frame allows for increased understanding of how an individual's culture is developed through the incorporation of the totality of one's experiences, interactions, and thoughts with the norms and expectations one perceives as being held by other group members. By understanding a group's values, belief systems, and ways of thinking and behaving, researchers, care providers, and policymakers can be better equipped to identify the cultural influences that serve as barriers and facilitators to eliminating health disparities.

Second, as the nation continues its discussion on health care reform,⁴¹ there is a need to highlight the health disparities and issues of social injustice among our most vulnerable populations such as the elderly. As Evelynn Borrayo and colleagues (2002) state, "The development of a closer link between services and needs will become increasingly important for policymakers as the population needing long-term care services grows and the pressure on state and federal fiscal resources mounts over the next several years."⁴² However, as policies are developed, special attention needs to be given to certain subpopulations, such as older African Americans and their caregivers. These groups have unique diagnostic and care management needs when compared to the general population. For example, as discussed earlier in this paper, African American elders are more likely than whites to be diagnosed with Alzheimer's disease at higher levels of cognitive impairment. Additionally, African American families are less likely than whites to institutionalize elders with dementia and more likely to normalize dementing behaviors.⁴³ Thus, informing African American families of treatment alternatives and training family members to adapt to the behavioral changes that accompany a dementing illness may prevent the deterioration of patients and their caregivers.⁴⁴ Equally important is the need for health care providers to understand that even when an individual's positive or negative views on dementia affect whether or not one will actively seek and use resources available to them, care is still needed. Thus, providers and patients and their caregivers are in a conundrum that can be eliminated to benefit all involved, resulting in the creation and sustainability of a just and equal health care system and society.

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