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11-1-2005

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Tarver, Dolores D., "Developing a Culturally Responsive Intervention for African American Caregivers: Encouraging Partnerships Between Universities, Medical and Mental Health Agencies, & Faith-Based Organizations" (2005). 10th Annual National Conference (2005): Different Perspectives on Majority Rules . Paper 38. http://digitalcommons.unl.edu/pocpwi10/38

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Abstract

The goals of the presentation are to: 1) raise awareness about the "silent epidemic" of Alzheimer's Disease and Related Disorders (ADRD) in the African American community and factors that influence caregivers' decisions to seek help; and 2) present a proposed model of culturally responsive services based on African worldview.

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Due to the limited representation of African American caregivers in the literature, the prevalence of African Americans with and projected to have Alzheimer's Disease and Related Disorders (ADRD), health disparities associated with the African American Alzheimer's population, and the lack of intervention research that addresses cultural dynamics, there is a need for research that addresses African American caregivers of elders with ADRD. The purpose of this presentation is to discuss a culturecentered intervention for African American caregivers and care recipients with ADRD.

This presentation can be useful to departments in university institutions that provide any type of human service such as counseling, outreach, or medical services to underserved groups. The researcher asserts that predominately White institutions need to take a more active role in raising awareness about health concerns for underrepresented groups and partnering with community agencies and faith based organizations to provide needed interventions—particularly in the African American community. The cycle of poor health is having an adverse affect on students enrolled in higher education as well as faculty and staff. The longevity of African Americans is declining due to factors associated with inadequate diets and accessibility to health care.

Over the next thirty years, the number of African Americans who will reach 65 and older will be approximately 6.9 million placing many elders at risk for debilitating cognitive diseases (Alzheimer's Association, 2004). In order to serve the estimated millions of African Americans expected to be at risk for ADRD, a culturally responsive intervention is needed. In an increased effort to improve care and support for the ADRD population, researchers in medical, social service, and other health related fields are attempting to reach an underserved group of African American elders and their caregivers who are in need of formal and informal care resources (Baker, 1994; Heyman et al., 1991). The author proposes a theoretically-based, culturally competent model for service delivery that incorporates an African worldview.

Current interventions for caregivers may not be consistent with the types of support utilized in African American communities. African American caregivers tend to rely on

more informal care networks when caring for loved ones with ADRD. *Informal care services* refer to help provided by a non-paid person or organization (Bullock et al., 2003; Travis, 1995). Typically these services provided by friends and family members involve affective care (emotional support) as well as functional care (help with various tasks of daily living (Travis, 1995). Family and spirituality have been strong sources of support for African American survival as well as flexibility in familial roles, a humanistic or communal orientation, and the ability to endure through tremendous suffering (Ho, 1987a; Littlejohn-Black & Darling, 1993). These studies have highlighted the importance of spirituality and religion not only in fostering resilience, but also as guidance in making decisions for impaired elders (Swanson, Spencer, Dell'Angelo, Harpalani, & Spencer et al., 2002).

Formal care services refer to help provided by people who receive monetary compensation for services. Providers are typically affiliated with a service organization. Examples of formal care services include, but are not limited to, adult day care, home health care, respite, nursing homes, transportation, meals, geriatric care, mental health care, and financial management (Bullock et al., 2003). Factors found to influence formal service utilization are perception of caregiver responsibilities, individual and family ethos (political and religious orientation and past experiences with formal networks), prior use of services influence utilization patterns, accessibility to and availability of services, demographic characteristics, and factors related to illness (stage, duration, etc.; Andersen & Newman, 1973) Teresi, Toner, Bennett, & Wilder (1988-89). Guarnaccia (1998) asserts that for African American caregivers, when elders are hospitalized for injury, family and community resources were often already in place, and caregivers were reluctant to accept psychiatric referrals. The researcher suggests that factors such as cultural mistrust, culturally inappropriate interventions, and lack of a culturally specific framework for understanding caregivers may influence service utilization.

Whereas, the recognition that African American caregivers rely more on informal networks exists, there is little empirical evidence to support the reasons why caregivers choose familial and community networks more often. However, the researcher suggests that factors such as cultural mistrust, culturally inappropriate interventions, and lack of a culturally specific framework for understanding caregivers may influence service utilization. Therefore, the researcher proposes an African-centered intervention that incorporates spirituality as well as both informal and formal resources. The researcher suggests the following components: family psychoeducational workshops offered through counseling psychology programs and other health agencies in the community, family support groups housed in local churches, and culturally responsive family respite programs that offer day care services as well as family skill development. Interventions should be long-term and focus on African American family strengths, medical information, and Community agencies. Programming would be strength-based and human service providers would be encouraged to understand family systems, coping mechanisms, and views about illness.

The presentation goals are to raise awareness about the silent epidemic of ADRD, discuss factors that may increase susceptibility to ADRD, describe the role of informal and

formal support networks in the caregiving process, and finally describe a culturally responsive model that incorporated African worldview, spirituality, and collaborations between universities and various organizations in communities.

Presenter

Dolores D. Tarver is a lecturer in the Department of Educational Psychology at the University of Nebraska-Lincoln. She is also a doctoral candidate in the Counseling Psychology Department and is currently collecting data for her dissertation on African American caregivers. Her areas of interest are multicultural education and counseling competency, culturally competent ethical codes, service delivery to underserved and underrepresented populations, African psychology, couple and family counseling, parenting, and community education. She completed her BS at Xavier University of Louisiana in May 1998 and her MA in Counseling Psychology from the University of Nebraska-Lincoln May 2001. She completed a APA approved pre-doctoral internship at the University of Memphis. She co-authored one book chapter, Caldwell, L.D. and Tarver, D.D. (2004). An ethical code for racial and cultural practice. In R. Carter (Ed.), *Handbook of racial cultural counseling and psychology, Vol. 2* and has submitted a manuscript for review, Caldwell, L.D., Iwamoto, D., Herzberg, S., Tarver, D., Cerda, P., Mack, T. (submitted for publication). *Perceptions of multicultural counseling competency: A provider's perspective*.