

GIVING VOICE TO RURAL AFRICAN AMERICANS' STORIES OF LONG-TERM CARE DECISION MAKING

Yvonne D. Eaves, PhD, RN
The University of North Carolina at Chapel Hill
School of Nursing
Carrington Hall, CB # 7460
Chapel Hill, North Carolina 27599-7460

Introduction: The elimination of health disparities among racial and ethnic minorities is a major goal of Healthy People 2010 as well as the focus of a national agenda endorsed by researchers, healthcare professionals, funding agencies and local, state and federal governments. As part of a strategic plan to address health disparities, the National Institute on Aging has set forth a goal to “advance aging research closer to the ultimate objectives of reducing and eliminating health disparities among older racial and ethnic minorities”. Older African Americans have a higher incidence of chronic illnesses and disabilities than older European Americans and rural older adults are in poorer health with less access to health care services than urban older adults. Thus, health disparities for older African Americans are compounded when rurality is added to the equation and we can expect a continued growth in family caregiving in this group. Similarly, African Americans suffer from disparities in community based services, nursing home use, and post-hospital discharge planning. A limited number of studies have examined how African American families make the decision to institutionalize their older adult relative. Moreover, no published studies were found on this topic that included rural African Americans in the sample. Thus, the voice of this sample is silent in the literature to date.

Purpose: The purposes of this study were to: (a) identify and explain transitions that occur over a two year course of the caregiving process and (b) examine the family decision-making process of rural African Americans who relinquished their caregiving roles and placed their older adult relative in a long-term care facility.

Method: Eleven rural African American caregiving families participated in this grounded theory study. Care recipients were either placed in LTC prior to entry into the study, during the study, or continued to be cared for at home. Data were generated by semi-structured interviews and focused observation sessions. A synthesis technique to grounded theory data analysis that incorporated the constant comparison method was used to analyze the data.

Findings: The findings and interpretations to be discussed in this paper are Stage I—Who Gets to Decide and Stage 2—Transitioning Care. Stage I strategies included: (a) family gathering and (b) physician dictated. Stage II strategies included: (a) resistance, (b) fear, (c) death preferred, (d) willing to make sacrifices, (e) accepting the inevitable, and (f) making desires known. Knowledge gained from hearing the voices and understanding the perspectives of rural African American families may help researchers to develop interventions that assist: in nursing home selection, with the decision-making process, with conflict resolution, and with the transition from home to institutional care.