HEALTH-RELATED QUALITY OF LIFE AMONG AFRICAN AMERICANS WITH MULTIPLE SCLEROSIS

Robert J. Buchanan, PhD; Chunfeng Huang, PhD; Bonnie J. Chakravorty, PhD

Objective: Identify factors associated with health-related quality of life (HRQOL) among African Americans with multiple sclerosis (MS).

Design: A survey cohort was recruited from the Registry of the North American Research Committee On Multiple Sclerosis (NARCOMS) Project. Data were collected from 131 African Americans with MS, with 111 participants providing all data needed for analyses of physical domains and 103 participants providing all data needed for analyses of mental health domains of HRQOL using multiple linear regression models.

Results: Worsening MS symptoms and greater interference of MS symptoms with daily life were associated with significantly lower physical domains of HRQOL. Respondents reporting that their principal care physician who had a greater understanding of how MS symptoms affected their daily lives tended to have significantly higher physical dimensions of HRQOL. A previous diagnosis of depression and agreement that participants were sometimes embarrassed in public due to their MS were associated with significantly lower mental health aspects of HRQOL.

Conclusion: Findings highlight the importance of the positive association between the level of understanding by the principal care physician of how MS symptoms affect the lives of African Americans and their physical dimensions of HRQOL. Physicians treating African Americans with MS need to understand how MS symptoms impact the life of these patients as a key component to providing culturally competent care. (Ethn Dis. 2011;21(3):377–384)

Key Words: Multiple Sclerosis, African Americans, Health-related Quality of Life

INTRODUCTION

Between 3% and 5% of people with multiple sclerosis (MS) in the United States are African American.1,2 Weinstock-Guttman et al found that African Americans were diagnosed with MS at a younger age, more likely to have greater disability with increased disease duration, and demonstrated a more rapid and severe cognitive decline.3 In a later study Weinstock-Guttman et al concluded that African Americans with MS have more rapid disease progression than Caucasians with MS, with greater tissue damage and faster lesion volume accumulation possibly explaining this rapid clinical progression.4 Other studies have observed that African Americans with MS are at risk for a more rapidly disabling disease course, with more disability compared to Caucasians with MS.5,6 Marrie et al found that African Americans experienced greater disability associated with MS than Caucasians but failure to adjust for socioeconomic differences overestimates these differences.7

The objective of our study was to identify factors affecting the health-related quality of life (HRQOL) of African Americans with MS. Previous studies analyzed HRQOL among people with MS, identifying demographic, MS-disease characteristics, and treatments that impact HRQOL. However, no previous study focused on the HRQOL of African Americans with MS. We built on these earlier studies of HRQOL in adults with MS to determine whether there were unique factors associated with the HRQOL among African Americans with MS. Learning more about characteristics associated with better HRQOL among African Americans with MS will facilitate the development of services and programs that address this community’s health needs, as well as identify areas for future study.

HEALTH-RELATED QUALITY OF LIFE AND MS

Multiple sclerosis has physical, psychological, and social impacts on the patient,8 with the unpredictability and stress of the disease affecting quality of life.9 The HRQOL measure reflects a person’s total well-being, including measures of social roles, physical health and symptoms, emotional status, psychological, and social well-being and not just the absence of disease or infirmity.10 The measure provides a broader measure of disease burden than physical impairment or disability levels,12 approximating the World Health Organization’s definition of health as including physical, mental and social well-being and not just the absence of disease or infirmity.10

Demographic Characteristics

Studies show that men with MS have higher HRQOL than women for various dimensions of HRQOL.13 Another study found that age was not associated with HRQOL among people with MS.14 Employed people with MS...