

Research Paper

Racial-ethnic variations in paid and unpaid caregiving: Findings among persons with traumatic spinal cord injury

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Abstract

Background: The effects of race-ethnicity on the use of paid and unpaid caregivers for those with spinal cord injury (SCI) have received little attention in the literature.

Objective: Compare the amount of paid and unpaid caregiver hours received and sources of caregiving between non-Hispanic White and non-Hispanic Black participants with SCI, controlling for demographic, injury-related, and economic variables.

Methods: Participants were identified from a large specialty hospital. Self-report data were collected by mail. Five aspects of caregiving were assessed: (a) paid assistance hours, (b) satisfaction with care, (c) unpaid assistance hours, (d) sources of informal care, and (e) evaluation of whether needs were met.

Results: Whites were more satisfied with paid care. Approximately 43.4% of Whites received informal care from their spouse every day, 14.7% higher than Blacks. Blacks were more likely to receive informal care from other family members, friends, church, and others. When controlling for gender, injury severity, chronological age, and years post injury, Blacks reported 1.50 more paid assistance hours (95% CI, 0.31–2.68 hours) and 1.83 less unpaid assistance hours than Whites (95% CI, 0.25–3.41 hours). Differences diminished and were not statistically significant after adding marital status and income into regression models.

Conclusions: The results did not provide strong evidence of racial disparities regarding caregiver assistance for those with SCI. Level of income appears to be directly related to satisfaction of quality caregiving and the use of paid versus unpaid care for those living with SCI. © 2015 Elsevier Inc. All rights reserved.

Keywords: Spinal cord injuries; Caregivers; Race; Ethnicity; Health care disparities

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According to the United States Census Bureau,¹ nearly 18.7% or 56.7 million people in the United States live with a disabling condition, and approximately 12.6% or 38.3 million have a severe disability. Severe disabling conditions require the ongoing assistance of a caregiver, whether formal (e.g., paid assistant) and/or informal (e.g., unpaid caregiver such as a spouse or family member).

Traumatic spinal cord injury (SCI) is a severe disabling condition that may result in permanent sensory and motor loss and, depending on the severity of the injury, requires an extended inpatient hospitalization and caregiving assistance with activities of daily living (ADLs), such as self-care, and instrumental activities of daily living (IADLs) like shopping and housekeeping. Nearly 65.7 million people in the United States are informal caregivers to an adult or child who is ill, disabled, or elderly; moreover, seven out of 10 caregivers take care of persons 50 years of age or older.² In 1990, the annual value of informal caregiving amounted to an estimated \$18 billion³ compared to an

approximate \$450 billion per year⁴ in 2009. As the number of people with disabling conditions rises,¹ longevity increases,⁵ and informal caregiving estimates accelerate,^{3,4} both formal and informal caregiving will steadily rise and become increasingly important to study. These noteworthy findings have challenged researchers, long-term care program planners, and policy makers alike to take an all-inclusive look at those responsible for caring for vulnerable populations.

Caregiver research has increased over the past several years; however, the effects that race, ethnicity, and culture have on paid or unpaid assistance in the population living with traumatic SCI has received relatively little attention. For example, someone with SCI who is not married or has a low socioeconomic status may rely on paid assistance versus someone with SCI who is married and may utilize his or her spouse (unpaid assistance) as the primary caregiver. These external (economic factors) and personal (marital status) factors may impact how those with SCI determine which type of care would be beneficial to their circumstance. Informal and formal assistance may vary based on race, ethnicity, and cultural expectations for those living with SCI; it is important that researchers continuously investigate caregiving assistance to identify cultural trends and variations determined by race and ethnicity.

The existing literature suggests Blacks tend to use informal caregiving or unpaid family assistance significantly more than Whites due to varying reasons,^{6–8} including cultural expectations.⁹ Black informal caregivers tend to provide increased and more extensive care compared to White caregivers in varying populations.^{8,10} For example, in an elderly community with residents ages 65 and older, McCann et al⁸ reported Black informal caregivers provided an average of 12.8 more hours of care each week than their White counterparts. Additional research studies provide examples in which Blacks¹¹ and Latinos¹² provide more informal caregiving assistance than Whites. Continuous and methodical investigation of race, ethnicity, and culture, which considerably impact types of assistance, can identify and explain trends and variations, coordinate efforts of program planners and policy makers, and improve long-term disability caregiving policies and services for people with a disability and caregivers alike. When examining types of assistance based on race, ethnicity, and culture, it is important to note caregiving hours of assistance may also differ based on the severity of disability or illness (mental and physical).

Various disabling conditions render incapacitating effects on survivors who are dependent on extensive caregiving assistance to perform ADLs/IADLs. As seen with previous research documenting minority caregiving assistance,^{6–9} Blacks with SCI may tend to utilize informal caregiving assistance substantially more than Whites. Although approximately 66% of SCI events occur in the White population, Blacks and other minority groups with SCI experience a higher rate of complications (e.g.,

pressure ulcers, urinary tract infections, and fractures) and are less likely to be discharged to an acute rehabilitation center.¹³ Thus, many minorities with SCI are left to rely significantly on caregiving assistance in their home. Comparably, minority stroke survivors have a reduced Functional Independence Measure (FIM) score, a measurement of disability, than Whites¹⁴ and are more likely to be discharged home which may be contributed to increased minority social and familial support systems¹⁵ and informal care assistance. Although there is research regarding racial disparities related to access to rehabilitation services and FIM, the research is limited concerning types of caregiving assistance, race-ethnicity, and traumatic SCI.

Purpose and hypotheses

Our purpose was to compare paid (formal) and unpaid (informal) patterns of caregiver assistance between non-Hispanic White and non-Hispanic Black participants with SCI (hereafter referred to as White and Black), while controlling for demographic, injury-related, and economic variables. Additionally, we evaluated how various socioeconomic components (e.g., marital status and income) affect patterns of care and satisfaction with care. We hypothesized the following:

1. White participants will have a greater number of paid hours of assistance compared to Black participants.
2. Black participants will have a greater number of unpaid hours of assistance compared to Whites.
3. Black participants will be more likely than Whites to receive care from family, neighbors, and the community.

Methods

Participants

Participants were identified from records of a large specialty hospital in the Southeastern United States and are part of an ongoing longitudinal study. Eligibility criteria included: (1) a minimum age of 18 years, (2) traumatic SCI, and (3) at least 1 year post-injury. After eliminating 575 confirmed deceased cases and 21 ineligible cases, there were 2558 individuals in the overall participant pool. Of the 2558 surveys, there were 400 non-respondents and another 469 individuals who were lost because they could not be definitively contacted. This resulted in 1689 usable responses (66% response rate). Participants were considered ineligible if they had a non-traumatic injury or had fully recovered (self-reported). Because this study focused on differences in caregiver assistance, we included only those who reported the need for caregiver assistance regardless if they received care or not ($n = 796$). Of those 796 who reported the need for caregiving assistance, 760 participants actually received some sort of care; several participants

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