

Race-specific norms: Using the model of hypertension to understand issues of race, culture, and education in neuropsychology

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Abstract

Development of appropriate and clear guidelines for proper use of neuropsychological tests among ethnic minorities is a current and significant challenge. Although development of race/ethnicity-specific norms is popular, it is also controversial. Some have argued that these norms will improve the sensitivity and specificity of neuropsychological measures in detecting cognitive impairment. However, two major arguments have surfaced that: (1) race-specific norms ignore underlying cultural and educational factors for which race serves as a proxy, and (2) setting “more lenient” cutoffs for impairment among ethnic minorities denies these groups needed services. In this paper, we argue that recent research on hypertension reveals a number of crucial lessons for neuropsychologists who are struggling with this issue. The model of hypertension is helpful in understanding issues of construct validity in neuropsychological testing, and is also helpful in revealing possible underlying causes of poor cognitive test performance for which race serves as a proxy.

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The lack of empirically based guidelines for use of neuropsychological tests among ethnic minorities is a current and significant challenge for neuropsychologists in the United States. Despite recent and projected growth in racial and ethnic diversity, the most commonly used cognitive measures have been validated only among non-Hispanic, English-speaking Whites (Manly & Jacobs, 2001). One of the most popular, and yet controversial, response to this challenge is the development of race/ethnicity-specific normative standards. To date, normative data from several sources have been developed and published for African Americans and Hispanics who speak English and/or Spanish (see Artiola i Fortuny, Hermsillo, Heaton, & Pardee, 2000; Heaton, Miller, Taylor, & Grant, 2004; Lucas et al., 2005; Ponton et al., 1996). These norms correct for age, years of school, and sex, and are meant to be applied to individuals when they identify as African Americans or Hispanics. Several researchers have argued that use of these norms will improve the sensitivity and specificity of neuropsychological measures in detecting cognitive impairment (Ardila, 1995; Lucas et al., 2005; Manly, 2005).

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Two major arguments have surfaced against the use of race-specific norms: (1) setting “more lenient” cutoffs for impairment among ethnic minorities ignores real deficits and potentially denies these groups needed services; and (2) separating normative data according to race introduces practical and theoretical problems since it ignores the underlying cultural and educational factors for which race serves as a proxy (Manly, 2005). We hope to shed light on this controversy by using the example of hypertension research to guide the discussion.

Before we discuss the hypertension model, a brief orientation is needed regarding our use of the term “normative data” and our basis for judging whether normative data are appropriately used. A detailed discussion of the purpose of norms in neuropsychological assessment is well beyond the scope of this paper, but there are several excellent publications dedicated to this topic (Busch, Chelune, & Suchy, 2005; Heaton, Taylor, & Manly, 2001; Mitrushina, Boone, Razani, & D’Elia, 2005).

1. General issues pertaining to use of norms among ethnic minorities

Neuropsychological test norms serve as a standard against which a person’s performance can be evaluated and then interpreted (Lezak, 2005; Mitrushina et al., 2005). Busch et al. (2005) elegantly shed light on basic considerations relating to normative standards when used among elderly people, distinguishing descriptive uses from diagnostic uses. This distinction is also useful in evaluating the goals of using norms among ethnic minorities.

When an individual’s performance is compared to a single reference group – for example, a group of people matched to the US population on age, sex, region of residence, race, and years of schooling – the normative data are being used *descriptively*. As long as the methods used to select that population are clearly delineated and properly operationalized, any population can serve as a reference if appropriate to the question at hand. For example, compared to a normative sample that is representative of the population of the United States, a score of 40/60 on the Boston Naming Test is likely to fall well below the average range. The person who obtains this score performs considerably below that of the average American, and thus this score can be considered unusual for this reference group. Now, consider that the individual who took the test is a bilingual 62-year-old Dominican-born Hispanic male with 6 years of school, who immigrated to New York City at the age of 20 and who was tested in English. We could still conclude that his score is considerably below that of the average American. However, in light of evidence to suggest that these background and demographic factors have significant independent effects on cognitive test performance (Manly and Jacobs, 2001), many neuropsychologists would consider comparing this Dominican man’s score to the average American inappropriate. In contrast, the comparison to the American reference group may have value in predicting a particular outcome, such as his ability to read, understand, and act on medical instructions given in English (Wilson, 2003; Youmans & Schillinger, 2003; Zarcadoolas, Pleasant, & Greer, 2005).

Descriptive normative data can also be more specific than “the US population” and thus may be more appropriate for certain clinical and research questions. Using the example above, we could compare his score to a representative sample of one hundred 60 to 65-year-old Hispanic men who have 4–6 years of school, and are administered the Boston Naming Test in English. As compared to this reference group, a score of 40 in the Boston Naming Test may now fall within the average range. Demographically focused reference groups are appropriate for describing an individual’s performance as it relates to people with similar backgrounds, but we should not assume that every background variable that relates to test performance has been considered in the reference group. Again referring to our example, what if all of the men in the reference group immigrated after age 50? Does level of English proficiency significantly affect Boston Naming Test scores in this cohort of bilingual individuals? Although a score of 40 may fall within the average range for Hispanics in New York, does this change if the reference samples were collected in Miami, North Carolina, or central California?

Normative data may also be used to diagnose cognitive impairment (Busch et al., 2005; Heaton et al., 2001). In this case, the purpose of norms is to provide a best estimate of an individual’s premorbid or expected score to which the current score can be compared. If the normative sample was selected appropriately, cutoffs can be generated that should provide good diagnostic validity, using indices such as sensitivity and specificity, positive predictive value, and likelihood ratios (Smith, Cerhan, & Ivnik, 2003). It should be clear that when norms are used for diagnostic purposes, background variables are likely to be crucial determinants of premorbid ability. Nevertheless, even in the diagnostic setting, it should not be assumed that we have taken into account all of the background factors that will improve the diagnostic validity of a measure. Returning to our example, we could compare his score on the Boston Naming Test to a representative sample of one hundred 60 to 65-year-old Hispanic men with 4–6 years of school, and who had no

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