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Introduction to the Neuropsychological Norms for the U.S.-Mexico Border Region in Spanish (NP-NUMBRS) Project

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Abstract

Objective: The present introduction to the Neuropsychological Norms for the U.S.-Mexico Border Region in Spanish (NP-NUMBRS) project aims to provide an overview of the conceptual framework and rationale that guided the development of this project.

Methods: We describe important aspects of our conceptual framework, which was guided by some of the main purposes of neuropsychological testing, including the identification of underlying brain dysfunction, and the characterization of cognitive strengths and weakness relevant to everyday functioning. We also provide our rationale for focusing this norm development project on Spanish-speakers in the United States, and provide an outline of the articles included in this Special Issue focused on the NP-NUMBRS project.

Conclusions: The data presented in this Special Issue represent an important tool for clinicians and researchers working in the neuropsychological assessment of Spanish-speakers in the United States.

With numbers of Spanish-speakers in the United States (U.S.) that exceed the population of many Latin American countries, neuropsychologists are often faced with the need to evaluate members of this heterogeneous language group. A limited armamentarium of tools

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In accordance with Taylor & Francis policy and ethical obligation as a researcher, Dr. Heaton is reporting that he receives royalties from the publisher of the Wisconsin Card Sorting Test-64 item, which is one of the tests included in this norming study.

for this purpose compromises competent diagnostic assessment in these populations. The goal of this introduction to the Neuropsychological Norms for the U.S.-Mexico Border Region in Spanish (NP-NUMBRS) project is to provide the reader with an overview of the conceptual framework and rationale that guided the development of demographically-adjusted normative data for a comprehensive battery of neuropsychological tests to be used with primarily Spanish-speaking adults living within the U.S.-Mexico border region. We briefly review the application of demographic adjustments, the advantages and limitations of population-specific norms, and the value of generating norms across a battery of tests with the same sample. We describe the rationale for our focus on the U.S.-Mexico borderland, and we set the stage for the collection of articles that appear in this special issue. We close with some general cautions about the applicability and limitations of the resulting norms.

Importance and uses of demographically-adjusted normative data.

One major purpose of neuropsychological assessment is the identification of acquired brain dysfunction. This requires a way to estimate premorbid ability, as preexisting test results are almost never available for comparison. While advanced neuroimaging techniques have somewhat diminished the traditional role of neuropsychological testing in locating brain lesions, at least in regions of the world where such technology is widely available, neuropsychology continues to make important contributions to the detection and classification of brain disorders. This is especially true for the many conditions that are not readily identified via neuroimaging, such as mild closed head injuries and the early stages of progressive neurodegenerative disorders (e.g., Alzheimer's Disease). Importantly, because neuropsychological test performance can be impacted by factors that are not the result of underlying brain impairment, it has become accepted practice to adjust expectations for certain demographic characteristics that have consistently been found to have significant effects on test performance such as normal aging, exposure to formal education, and sex. These demographic effects may be somewhat different across cultural/racial groups (Heaton et al., 2004). Furthermore, there are other potential variables whose influences on test performance are more difficult to quantify, including socio-demographic, cultural, and linguistic factors; familiarity with testing; stereotype threat, and others. Here is where region or population-specific normative data that adjust for demographic factors within a population of interest could serve to improve diagnostic accuracy for brain dysfunction. Such population-specific norms do not necessarily identify all the relevant sociocultural or linguistic factors impacting test performance within a population, but they provide a constellation of characteristics to "adjust" for such factors. Furthermore, they can adjust for the potentially population-specific effects of easily identified demographic characteristics, and thus improve diagnostic accuracy.

Of note, we do not espouse the use of demographically-adjusted population-specific norms as the sole approach to addressing current diagnostic challenges when working with culturally/linguistically diverse populations. While normative adjustments are a viable approach and represent an important tool, they are not a panacea for the challenge of conducting valid and meaningful neuropsychological evaluations and interpreting neuropsychological data with diverse populations. In this regard, use of appropriate, demographically-adjusted norms is just one part of a culturally-competent

neuropsychological evaluation. Other, equally-important components of a neuropsychological evaluation typically include clinical interviews with patients and others who know the patient well (e.g., family members, close friends, caregivers) in order to capture important aspects of the patient's background (e.g., sociocultural, linguistic, educational, occupational, medical, psychiatric and substance use backgrounds), as well as administration of self-report questionnaires (e.g., mood and other psychiatric symptoms, neurobehavioral symptoms, everyday functioning) and review of available medical and other pertinent records. Furthermore, a culturally-proficient approach to neuropsychological evaluations entails awareness of one own's worldview and that of the examinee, and the acquisition of culturally-appropriate assessment and communication skills necessary to effectively work with members of the examinee's group. It requires understanding of important aspects of the examinee's culture and the sociopolitical context in order to best consider them in the collection and interpretation of all data gathered over the course of the evaluation, including during the clinical interview, record review, and interview with family members/caregivers (American Psychological Association, 2017; Sue, Zane, Nagayama Hall, & Berger, 2009). Importantly, it also requires the neuropsychologist to identify and consider background characteristics of the particular examinee that may be different from those of the people who provided data for the available norms. When working with Spanish-speaking examinees understanding commonly shared experiences and values of the Hispanic/Latino culture, can help inform the evaluation approach. For example, considering the varying degrees of acculturation and knowledge of English and Spanish in this group, the clinician might assess proficiency in each language early on in the evaluation in order to inform the language in which the evaluation ought to be completed. Some instruments which might be helpful in this regard include self-report measures (Birdsong, Gertken, & Amengual, 2012; Mungas, Reed, Crane, Haan, & Gonzalez, 2004), as well as performance-based assessments of fluency in English and Spanish (Suarez et al., this issue), and naming abilities (Ivanova, Salmon, & Gollan, 2013; Stasenko, Jacobs, Salmon, & Gollan, 2019). Similarly, considering the high importance placed on the family in the Hispanic/Latino culture (*familismo*), the clinician might consider involving family members early on in the evaluation while describing its purpose and conducting the clinical interview when feasible.

Advantages of demographically-adjusted normative data on a comprehensive battery of neuropsychological tests.

In addition to identifying brain dysfunction, neuropsychological testing is also helpful in determining cognitive strengths and weaknesses that are important for everyday function. In many cases, the presence of brain injury or disease is clear from history and/or other diagnostic procedures, whereas neuropsychological testing can be critical in describing the nature of the resulting cognitive deficits and enduring strengths. An important tool in characterizing the pattern of neuropsychological test performance is the practice of co-norming instruments across a comprehensive neuropsychological test battery. Co-norming involves generating normative data for a neuropsychological test battery within the same reference population at the same point in time (Lucas et al., 2005). Co-normed neuropsychological batteries allow for the analysis of an individual's cognitive profile, directly comparing performances across different cognitive domains, that cannot be

interpreted with equal confidence from a collection of stand-alone tests with their own normative reference groups, thus facilitating diagnostic decision-making (Lezak, Howeson, Loring, & Fischer, 2004). This consideration of relative strengths and weaknesses contributes to the overall interpretation of results in relation to an individual's cognitive profile and clinical diagnosis, as well as informing prospects for success or needs for assistance in activities of daily living. While our co-normed comprehensive battery allows identification of strengths and weaknesses across several domains, in this Special Issue on the NP-NUMBRS project we did not directly investigate the link between test performance and everyday functioning. For now, this limits the utility of the battery in predicting success in daily activities among borderland Spanish-speakers. Future research might shed light on the degree of impairment that is necessary and sufficient to interfere with everyday functioning in this population, considering that the past experiences of examinees can modify the impact cognitive impairment on successful performance of a specific activity. Relatedly, absolute level of performance (instead of demographically adjusted data) might be best suited for the prediction of ability to perform specific activities (e.g., those that most adults would be expected to perform, like safely driving a car or paying bills).

Focus on Spanish-speakers living in the U.S.-Mexico border region.

The terms Hispanic or Latino have been used in the United States (U.S.) to refer to a person of Cuban, Mexican, Puerto Rican, South or Central American, or other Spanish culture or origin regardless of race (U.S. Census Bureau, 2011, 2018, 2019a). U.S. Hispanics/Latinos are quite heterogeneous, with varied national origin, immigration patterns, acculturation, and language use, which is evident by the various terms that are used to refer to this group in the U.S., i.e., Hispanic/Latinx/Latina/o (Healy, 2010; Taylor, Lopez, Martinez & Velasco, 2012). While there are differences in the origin, sociopolitical background, and preferences for each of these terms (Lopez, 2013; Salinas Jr. & Lozano, 2017; Taylor, et al, 2012), in an effort to acknowledge this heterogeneity, these terms are used interchangeably in the various articles of this Special Issue, according to the preferences and practices of the lead authors. Hispanics/Latinos represent the largest racial/ethnic minority group in the U.S., comprising 18% of the population (Bureau Census, 2018b) Of the nearly 54 million Hispanics/Latinos age 5 and over in the U.S. in 2017, 72% (close to 40 million) spoke Spanish at home (U.S. Census Bureau, 2017b). Despite the large number of Spanish-speakers, there is a paucity of Spanish language tests with accompanying normative data suitable for U.S. populations (see Morlett Paredes, Gooding et al, Under Review, in this Special Issue for a review). While the primary or best language spoken is clearly a factor that ought to be considered in neuropsychological testing, there are also other aspects of the Spanish-speaking population in the U.S. that make their neuropsychological evaluation particularly complex. In addition to differences in national origins, an estimated 58% of Spanish-speakers age 5 and over in the U.S. also speak English very well (U.S. Census Bureau, 2017b) and prior findings indicate important influences of bilingualism on test performance (Bialystok et al., 2009; Bialystok & Poarch, 2014; Luo, Luk, & Bialystok, 2010; Rivera Mindt et al., 2008). This raises questions about both selecting the best language for testing as well as how to consider the potential impact of bilingualism in the identification of cognitive impairment among persons who speak primarily Spanish but may also speak English. In the article on our

methodology (Cherner, Marquine et al, 2020), we detail how we determined best language and excluded from the normative sample persons for whom English was their better language. In addition, the article by Suarez et al. (Under Review) examines effects of degree of bilingualism (defined as a ratio of verbal fluency in English to verbal fluency in both English and Spanish) on test performance in our sample of primary Spanish-speakers.

As by far the majority of the U.S.-dwelling Hispanic/Latino population is of Mexican origin/descent and has a high proportion of primary Spanish-speakers, the norms generated as part of the NP-NUMBRS project stand to make an important contribution to neuropsychological services and research with this group. Our sample was recruited in the borderland regions of San Diego, CA and Tucson, AZ. The proportion of Hispanics/Latinos in these states exceeds a third of the population in those states (39% in California, and 32% in Arizona; U.S. Census Bureau, 2019d), both of which approximate the proportion of Hispanics/Latinos in Texas, with an estimated 40% Hispanic/Latino population (U.S. Census Bureau, 2019d). While at first glance it would appear that some of the characteristics of Spanish-speakers in these three states are generally similar (e.g., high degree of biculturalism and bilingualism, high proportion of Hispanics/Latinos of Mexican origin/descent), empirical investigation is needed to confirm that our norms behave similarly in Spanish-speakers from Texas.

In this Special Issue we provide normative data for a battery of tests covering seven cognitive domains: verbal fluency (Marquine, Morlett Paredes et al., Under Review), speed of information processing (Suarez, Diaz Santos et al., Under Review; Rivera Mindt, Marquine et al., 2020), attention/working memory (Gooding et al., 2020; Scott et al., 2020), executive function (Suarez, Diaz Santos et al., Under Review; Marquine, Yassai-Gonzalez, et al., 2020; Morlett Paredes, Carrasco, et al., 2020), learning and memory (Diaz Santos et al., Under Review), visual-spatial skills (Scott et al., 2020), and fine motor skills (Heaton et al., 2020). We provide normative data on these tests derived from polynomial equations, which allow for the consideration of linear and non-linear effects of demographic factors on test performance. We present regression formulae to derive demographically adjusted scores for each of the tests in the battery, taking advantage of the full range of values in continuous variables (age and education). We provide a digital calculator for ease of use and to avoid computational errors (see online Supplemental material). Other details of our methodological approach can be found in the paper by Cherner, Marquine, and colleagues (2020). In an effort to best characterize our sample (given the heterogeneity within the Hispanic/Latino population), and help clinicians and researchers best assess whether the normative data presented applies to their patients and participants, we provide available social, educational, and linguistic data on our cohort. How distinct this segment of the population might be from other Spanish-speaking groups in the U.S. in their neuropsychological test performance is an empirical question, and one that should be the focus of future research. As our field continues to ascertain which factors reliably predict test performance, future norms may add more granular adjustments to the traditional demographic corrections for age, education, and sex. For example, while we could not consider degree of bilingualism as a factor in the norms given limitations of the available data, as mentioned above, we examined the role of English-Spanish bilingualism on the entire battery of tests (Suarez et al., Under Review), and if future results warrant it, degree of bilingualism may become an adjustment to improve diagnostic accuracy. We also present

initial evidence of the validity of the present battery for the identification of neurocognitive impairment, by applying the NP-NUMBRS norms to a cohort of persons living with human immunodeficiency virus (Kamalyan et al., 2020). The final paper in the issue integrates important findings across the different articles and provides a roadmap for future research (Rivera Mindt, Aghviniana et al., Under Review).

We invite you to explore our normative effort and hope that you will find our contribution an important improvement to the state of neuropsychological assessment for U.S. Spanish-speakers.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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