

COMMENTARY: A PROPOSITION AGAINST USING THE TERMS “HISPANIC” AND “LATINO” IN RESEARCH ON HIV-ASSOCIATED NEUROCOGNITIVE DISORDERS

In the United States, the term “Hispanic” has been used to refer to a person or groups of persons who originate from Spanish-speaking countries. However, this term fails to account for variables such as nationality, ethnicity, race, and cultural origin as well as the extent of assimilation to a new culture. In addition, factors such as the individual’s generation, specific migratory status, years of education in each country, fluency, and day-to-day language usage contribute to variance in neuropsychological testing outcomes, which are sensitive to these factors. We have noted that the usage of the terms “Hispanic” and “Latino” is problematic in HIV-associated neurocognitive disorder (HAND) research; therefore, we propose grouping individuals by nationality or by the Spanish-speaking culture to which they belong. The rationale for not using these terms is based upon the sociodemographic findings among Spanish speakers infected with HIV and how these terms inadequately describe the rich heterogeneity of this population. (*Ethn Dis.* 2010; 20:479–484)

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INTRODUCTION

The principal goal of this work is to point out how the term “Hispanic” or “Latino” has been problematic in providing meaningful research results that allow us to accurately identify HIV-associated neurocognitive disorder (HAND) in Spanish-speakers who are HIV infected. Since its introduction in the 1970s, the term “Hispanic” was used to aid bureaucrats in categorizing populations of persons from different Spanish-speaking cultures who were residing in the United States. However, great controversy has been spawned in different areas of scientific research when describing research results based upon this composite term for Spanish-speaking populations, especially in the neuropsychological literature. The usage of the term “Hispanic” loses its credibility in the neuropsychological literature because it is highly over-generalized, and does not take into consideration important factors that affect neurocognitive functioning (e.g., culture, language, and ethnicity). The term “Latino/a” likewise is over-generalized and results in simplifications of the research results obtained with this heterogeneous group of populations. In fact, “Latino/a” generalizes to a yet larger group of individuals than “Hispanics.” The term “Latino” is used to designate those countries whose vernacular language is derived from Latin, or romance languages, which may include Spanish, Portuguese, French and Italian. Neither of these terms differentiate among the specific characteristics of the distinct nationalities that comprise “Hispanics/Latinos.” Not only is the national origin significantly different but the level of identification with one’s culture is significantly

different as well. Moreover, level of acculturation to the new culture is also an important factor to consider in the HAND literature. The more generations that pass, the more likely it becomes that the identification with the original culture diminishes, while the level of acculturation to the new culture increases.¹ Both terms do not take these factors into consideration.

Combining the different groups of ethnic groups that originate from different Spanish-speaking cultures in one word like “Hispanic” or “Latino” has created difficulties when studying specific populations. Consequently, when studying this group of populations, a propensity for misclassification stems from the heterogeneity of the subgroups to which they belong. In this context, it is important to emphasize the existing differences among populations of persons from Spanish-speaking cultures when we refer to ethnicity and race. Ethnicity refers to a specific social group that shares a common history, sense of identity, geographic orientation, and cultural roots. An example is a migrant farm worker who unites with others in the group solely to celebrate their traditions with people who share their same roots. Race, in contrast, refers to a group that shares similar physical characteristics. For example, in Cuba, race diversity exists within the population in which we can find different peoples of color. While the terms “Hispanic” and “Latino” are used to designate a population that may originate from multiple Spanish-speaking countries, these terms do not provide for the need to preserve the integrity of the subgroups merged. Fortunately, the field of neuropsychology has shown great interest in classifying persons from Spanish-speaking cul-

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tures in an appropriate way for valid evaluation by distinguishing the different populations contributing to this diverse group of cultures.²⁻¹¹

IS THE TYPE OF LANGUAGE USED AMONG SPECIFIC "HISPANICS" IMPORTANT IN THE HAND LITERATURE?

It is important to emphasize that Spanish is one of the most widely spoken languages in the world. Nearly 400 million people speak Spanish as their first language.¹² Spanish is spoken in more than 21 nations and other territories on five continents. Over the past five centuries, the Spanish language has extended throughout the Americas - from Northern Canada to Tierra de Fuego in South America.¹³ Within each country, sub-groups use Spanish for different reasons due to different histories of the peoples that shaped each nation's distinct cultural aspects. Therefore, the form that Spanish itself takes can be quite different in various countries using the language. In fact, more than 100,000 Spanish words have developed independently in Latin America and are not recognized in the *Real Academia Española*.¹⁴ For example, in Mexico, it is estimated that close to 90% of the population is of Mestizo descent, a mixture of European and indigenous native ancestries.¹⁵ In contrast, only 2% of the population in Argentina identifies as Mestizo and that population largely uses Italian language terms.¹⁶ Just as there are different blends of races in countries with diverse populations reflecting different countries of origin, there are different blends of their languages of origin in use as well.¹⁷ For example, in some Spanish-speaking countries Spanish has been more highly intermingled with native dialects than in others (e.g., Nahuatl, Quechua, and Mayan in Mexico). Some persons from Spanish-speaking cultures exhibit a more European influence than

those of other cultures, for example, Peru, Argentina, and the Caribbean have more Asian, Italian, and African influences, respectively,¹⁷ thus demonstrating the high level of heterogeneity of the Spanish-speaking population in the world.

The United States is one of the countries in which Spanish is used frequently. According to the US Census, it is estimated that 46.9 million (15%) of the population is descended from or was born in a Spanish-speaking country.¹⁸ By the year 2050, it is estimated that more than 100 million of the US population will be "Hispanic."¹⁹ A high level of heterogeneity among this population, in relation to national origin, is also demonstrated in the United States. Mexicans represent 58.5% of this population in the United States, followed by Puerto Ricans (9.6%), Central Americans (4.8%), South Americans (3.8%), Cubans (3.5%), and Dominicans (2.2%).¹⁹ Additionally, some of these individuals have been born in the United States while others have only recently immigrated. Moreover, it should be emphasized that the "Hispanic" population is unequally distributed throughout the United States, with most prevalence in the states of California (13,074,156), Texas (8,385,139), Florida (3,646,499), New York (3,139,456), and Illinois (1,886,933).¹⁹ More specifically, the majority of the "Hispanic" population can be found in the Los Angeles County, California (4,706,994); New York, New York (five counties of Bronx County; Kings County [Brooklyn], New York County [Manhattan], Queens County, and Richmond County [Staten Island]) (2,337,288); Harris County, Texas (1,484,311); Miami-Dade County, Florida (1,471,709); and Cook County, Illinois (1,200,957).²⁰ Additionally, there has been an increase in "Hispanic" populations in US counties where these populations were not traditionally seen before. For example, North and South Carolina are

the states with the highest percentage increases in their "Hispanic" population from 2007 to 2008.¹⁸

In the United States, one would expect variability in the Spanish language due to the variability of nations of origin. The type of Spanish language used, in this case, is an important neuropsychological variable when studying a specific "Hispanic" population that speaks Spanish in the United States. Neurocognitive scientists require the understanding of these subtle language particularities to conduct adequate HAND research. Scientists need to become familiar with the different Spanish linguistic variations that devolve from different nations of origin. Not only is the language of origin important but also the development of fluency in the language of the dominant culture is important as well. Initially, most immigrate as Spanish-speaking monolingual persons. In time, some become bilingual but will be able to communicate in the new language at different fluency levels. Subsequently, this results in different types of individuals: 1) persons who speak only Spanish; 2) persons who speak Spanish more than English; 3) persons who speak both equally well; and 4) persons who speak more English than Spanish. The process of moving from groups 1-4 continues as generations pass until the person speaks only English. For most people, when immigrating, the process of learning a new language starts immediately, progresses rapidly, and ends in approximately 15 years.⁷ In addition, various other authors have emphasized age as an important factor when learning a new language.²¹⁻²³ The younger the individual, the more rapid the learning process will be in learning English. For example, it has been reported that 70% of children aged 5 to 9 years use English regularly after the first 9 months in the country. By age 14, they use it highly frequently, and 30% of these youths prefer to speak English.²¹⁻²³

Level of acculturation affects the use of Spanish over the generations.¹ In addition, among bilinguals, there are different levels of language proficiency, which depends on the age at which the person learns English as their second language. These levels are summarized by those who learn a second language before age 12, after age 12, and those learning two languages simultaneously (coordinated bilingual) from early childhood.²¹ Nevertheless, little is yet known of the English language learning process of the immigrant adult in the neuroscience literature. It has been mentioned that this process is much slower than in children and that some will learn only the minimal amount of the second language while others will never learn a significant amount.

Neuropsychological literature has criticized studies of “Hispanics” when they are not evaluated in their primary language.^{21,22,24} It is obvious that this results, with some frequency, in an inadequate evaluation and diagnosis, as statistics show that 49% of the population does not speak English very well. What is also manifest is the inadequate use of neuropsychological tests in Spanish to evaluate the Spanish-speaking population in general – still without distinguishing the different types of Spanish by nationality and other variables such as acculturation, education, language fluency, and resources.¹⁹ The majority of persons who originate from Spanish-speaking countries have less access to medical and health care services, social services, and educational services than persons born in the United States. For this reason, the results of HAND research in which Spanish-speaking persons who speak different dialects of Spanish are grouped together could demonstrate different effects than if only people who speak the same dialect of Spanish are evaluated. A specific example of the issues mentioned above can be observed in different subtypes of “Hispanics” and “Latino(a)” who are infected by HIV.

The Example of HIV/AIDS

The epidemic of HIV/AIDS has been one of the most tragic in the world’s history. Consequently, specific health programs have been implemented to prevent HIV infection. However, statistics still show an increase in HIV cases worldwide and in the United States. The data on AIDS gathered by the World Health Organization (UNAIDS) indicate that at the end of 2007, 33.2 million people were living with HIV/AIDS (currently estimated at 40 million), and of these, 1.1 million were in the United States.²⁵ In North and South America, there are approximately 150,000 new cases of HIV infection per year. The majority of AIDS cases found in the Americas are in the United States, followed by Brazil, Mexico, Colombia, and Argentina.

Although the percentage of people living with HIV infection in Latin American countries is relatively low compared with the percentages found in sub-Saharan Africa, the number of people affected continues to be substantial and greater than that in the United States.²⁶ Moreover, the situation has the potential to worsen in Latin America where decreased prevalence of HIV has not occurred and the HIV epidemic is highly diverse. Of the Latin American nations, Brazil has the highest prevalence of HIV cases, with almost half the cases in the region. In that non-“Hispanic” Lusophone country, the rates of HIV transmission via heterosexual couples, men who have sexual relations with other men, and the re-use of syringes all have equal prevalence.²⁴ In addition, HIV type 2 is endemic in Brazil as well as HIV-1 (seen in the United States). In Argentina, HIV transmission was initially associated mostly with people who injected drugs and then with men who have sex with other men. Nonetheless, the virus has now extended to heterosexual couples.²⁷ In addition, the re-use of syringes in the medical setting in Bolivia, Ecuador, Guatemala, Haiti and Nicaragua (and

other Central and South American countries) has contributed to increases in contagion. These examples demonstrate how the HIV infected population may present heterogeneous risk factor characteristics by national origin.²⁸ Of note, heterogeneous risk factors require preventive treatments tailored to risk factor.

HIV/AIDS in the United States

The “Hispanic” population is the largest minority population in the United States. It is speculated that this minority group, due to its size, has great strength in resources, services, and support. However, the reality is that the “Hispanic” population in the United States experiences a wide variety of serious problems (e.g., poverty, risk of unemployment, lower level of education, and health problems). In general, this population has been disproportionately affected by a variety of conditions such as HIV/AIDS, diabetes mellitus, cirrhosis, homicide, and several types of cancer (i.e., uterine, hepatic, and gastric).¹⁹ In addition, they have poor access to preventive health care and effective treatments. As of late, people who speak Spanish continue to face difficulties in gaining access to basic health care, preventive health care, and medical treatment for HIV infection. In terms of statistics on the latter condition, it was estimated that HIV/AIDS was the fourth leading cause of death among men and women of “Hispanic” origin between the ages of 35 and 44. The prevalence of “Hispanic” HIV-infected men reported was 50.9/100,000, almost three times greater than that of Caucasians.^{13,28} Of these men, 57% were exposed by men having sexual contact with other men, 14% were exposed through high risk heterosexual contact, and 23% were exposed through injection of drugs. Similarly, the prevalence for HIV-infected “Hispanic” women, both adolescent and adult, was 15.1/100,000, which is more than 5 times the proportion of Cauca-

sian women (2.9/100,000). Seventy-one percent of “Hispanic” women were exposed through heterosexual contact, and 28% were exposed through injection of drugs. “Hispanics” represent 18% of the 35,314 newly diagnosed cases of HIV/AIDS in the 33 states that use notification systems for HIV positive serostatus.²⁷

IS THERE HETEROGENEITY AMONG “HISPANICS” BY NATIONAL ORIGIN IN REGARDS TO RISK BEHAVIORS?

It is particularly important not to combine all groups of persons from Spanish-speaking cultures as “Hispanics” when data are analyzed concerning HIV/AIDS. HIV risk factors vary significantly by country of origin when combining all Hispanics in the CDC database from 2001 to 2005. It can be concluded that the majority of “Hispanics” as designated are at a higher risk of acquiring HIV through male-to-male sexual contact (61%) and are at a lower risk via injected drugs (17%) and heterosexual contact (17%). Yet, we appreciate that this conclusion remains inadequate, as it does not account for the majority of problems that occur in specific “Hispanic” sub-groups and since it can cause grave errors when addressing the problems that occur in these specific populations. For example, the CDC data from 2001 to 2005 indicate that Puerto Rican Hispanics have a higher probability compared to other groups of acquiring HIV via injected drug use and less probability via high-risk heterosexual contact. Central Americans have a higher risk via heterosexual contact (45%) compared with male-to-male contact (41%) and injected drug use (11%). Likewise, those born in the Dominican Republic have a higher risk of acquiring HIV via heterosexual contact (47%) compared to male-to-male contact (30%) and

injected drug use (20%). These rates are also different from rates of those born in South America, Cuba and Mexico, where there is a higher risk of acquiring HIV infection through male-to-male contact: 65%, 62%, and 54%, respectively.²⁹

Proportionally more “Hispanics” with HIV infections live in Los Angeles County compared to the rest of the United States³⁰ and requires a specific focus in order to address HAND among primary Spanish speakers. Of note, approximately 75% of the “Hispanic” HIV infected population in the Los Angeles area is of Mexican descent.³¹ The population of primary Spanish speakers in Los Angeles could be highly susceptible to HAND because Mexicans are the least educated compared to “Hispanics” and other minority groups.²⁹ They are also least likely to seek medical treatment and most likely to discover their HIV positive serostatus very late in the infectious process.²⁹

FACING THE “HISPANIC” PROBLEM IN STUDIES OF HAND

Since the problem with using either “Hispanic” or “Latino” as an ethnic term is significant, we prefer to focus on finding a solution that takes into account those specific persons who are most affected and who are in most need of support, such as those infected with HIV. Using HIV/AIDS as an example may contribute solutions that will enable us to work with different types of “Hispanic” populations. The study of neurocognitive impairment in this population represents an opportunity to expose and explain the problem of grouping people who speak the same language – in this case, “Hispanics.” It is also an opportunity to observe how this grouping can adversely affect a disadvantaged population.

Recently, the nosology of neurocognitive disorders associated with HIV

infection has been updated, which has helped to describe possible solutions to the problem.³² However, professionals in the field of HAND should further contribute to solutions and support for the specific sub-types of this population. Few studies focus on the neurocognitive processes of the HIV infected “Hispanic” or “Latino” populations in the United States. With more specific findings, one can discover different routes of treatment for “Hispanics” infected by HIV. One of the greatest contributions made for this group has been the creation of a special battery to evaluate the HIV-infected “Hispanic” population in Miami, the HUMANS battery.^{33–35} This battery has been adapted to a least common denominator version of the Spanish language for use in the multi-cultural “Hispanic” population of Miami. It was subsequently successfully employed in Argentina using a separate version with respective modifications according to that homogenous culture. Moreover, it most recently has been translated into Portuguese for use among Lusophones in Brazil. Future projects that use the HUMANS battery are focused on the type of Spanish used in Los Angeles, Puerto Rico, and Mexico in order to further establish the use of this battery at a national and an international level for each sub-type of “Hispanic” or “Latino” who might present for neurocognitive evaluation. The existing adaptations of the HUMANS battery to each culture and/or region represent a strong option for appropriately characterizing neurocognitive impairment among persons with HIV infection who speak Spanish. They allow us to obtain reliable and valid information that may help us lend support to the treatment of HAND in these heterogeneous groups.

CONCLUSION

The terms “Hispanic” and “Latino” have been over-generalized and have

been used in scientific investigations in a manner that threatens the validity of the conclusions for HAND, as well as for other diseases. Our specific focus herein is on the elimination of the terms “Hispanic” and “Latino” in HAND research. These terms have become more sociopolitical than scientific. Likewise, they are inadequate to identify populations whose origins are from specific Spanish-speaking countries. In working toward a solution to this scientific problem, we propose to group these individuals by nationality and by region, with the intention of appropriately identifying the sub-group to which each of these individuals belongs. By identifying these sub-groups, we propose to disaggregate “Hispanicity” and instead, organize these people into groups belonging to the same race or ethnic group to study them (e.g., Mexicans, Salvadorians, Nicaraguans, etc.). Further, we suggest the substitution of “Hispanic” and “Latino” by the phrase “persons from Spanish-speaking cultures.” Also, the level of Spanish language fluency should be specified for scientific purposes.

One clear-cut example supporting the need for this change is the heterogeneity of HIV risk factors among persons from Spanish-speaking cultures. Among different Spanish-speaking ethnicities, we have noted data that reflect a great difference in HIV risk factors. As HAND researchers, we feel that there must be greater dedication to incorporate related research on cross-cultural issues among Spanish speakers. One objective of ours is to propose alternatives that offer a better opportunity to those who come from or who are part of Spanish-speaking cultures in the United States and internationally, in order to avoid the misapplication of sociopolitical terms (developed for administrative convenience) in the place of scientific terms. Finally, we suggest more emphasis on the need to specifically study those persons from Spanish-speaking cultures who are not only at high risk

for HAND but who also face significant barriers in accessing healthcare services. This highly vulnerable population with diverse issues cannot be expected to successfully rely upon the same privileges that the majority of the population has in regard to their basic health care in the United States, making it even more critical to focus on these specific vulnerable populations.

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COMMENTARY: USE OF POPULATION TERMINOLOGY IN RESEARCH - López et al

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