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Ethical and Methodological Considerations in Clinical Communication Research with Hispanic Populations

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Communication Disorders in Spanish Speakers

Theoretical, Research and Clinical Aspects

Edited by José G. Centeno,
Raquel T. Anderson and Loraine K. Obler

Communication Disorders in Spanish Speakers

Communication Disorders Across Languages

Series Editors: Dr Nicole Müller and Dr Martin Ball, *University of Louisiana at Lafayette, USA*

While the majority of work in communication disorders has focused on English, there has been a growing trend in recent years for the publication of information on languages other than English. However, much of this is scattered through a large number of journals in the field of speech pathology / communication disorders, and therefore, not always readily available to the practitioner, researcher and student. It is the aim of this series to bring together into book form surveys of existing studies on specific languages, together with new materials for the language(s) in question. We also envisage a series of companion volumes dedicated to issues related to the crosslinguistic study of communication disorders. The series will not include English (as so much work is readily available), but will cover a wide number of other languages (usually separately, though sometimes two or more similar languages may be grouped together where warranted by the amount of published work currently available). We envisage being able to solicit volumes on languages such as Norwegian, Swedish, Finnish, German, Dutch, French, Italian, Spanish, Russian, Croatian, Japanese, Cantonese, Mandarin, Thai, North Indian languages in the UK context, Celtic languages, Arabic and Hebrew among others.

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Chapter 8

Ethical and Methodological Considerations in Clinical Communication Research with Hispanic Populations

JOSÉ G. CENTENO and WILLARD GINGERICH

Conducting clinical communication studies with culturally and linguistically diverse (CLD) groups imposes challenges on the investigator. Particularly, research must be guided by sensitivity and respect to the population being studied, especially considering the realistic understanding of the different normative phenomena of the group (Kayser, 1995; Silverman, 1997). A crucial concern is ensuring that the development and implementation of the different steps of the research protocol reflect the typical social, cultural, socioeconomic, educational, and linguistic factors of the target group (Hammer, 2000; Kayser, 1995; Marín & Marín, 1991; Mertens, 1998). The investigators' lack of sensitivity to, and understanding of, the group's typical dynamics would seriously compromise even initial steps in the study, such as access to the community, as well as the ethical and methodological integrity of the research effort.

The purpose of this chapter is to provide an overview of the most important principles on clinical communication research with CLD populations with an emphasis on issues relevant to Hispanic groups in the USA. As ethics in research is integral to the planning and implementation of the research protocol, we will start with a discussion on the legal and ethical guidelines in clinical communication investigations. We will continue with descriptions of demographic and cultural aspects of the Hispanic community in the USA and consider the ramifications of these variables for the research process. Next, we will address methodological considerations in clinical communication investigations on Hispanic individuals in the USA. Finally, we will conclude with implications of the above discussions for future research in clinical communication in CLD groups, particularly in Hispanic communities.

Ethical Considerations in Research

The Code of Ethics of the American Speech-Language-Hearing Association (ASHA) considers the rights and welfare of research participants

of paramount importance (ASHA, 2002). ASHA's professional guidelines are consistent with the federal mandate on protection of individuals recruited to participate in research. In its *Belmont Report*, the National Commission for the Protection of Human Subjects in Biomedical and Behavioral Research (1979) identifies three ethical principles and six norms to guide research. The three ethical principles, namely, beneficence, respect, and justice, respectively describe the positive outcomes to humanity that research should have, the courteous and respectful treatment that research participants should receive, and ensures that procedures are nonexploitative and fairly administered. The six norms of scientific research emphasize the use of valid designs, the participation of competent researchers, the explanation of both compensation and possible consequences of the research methods to the participants, and the appropriate selection and voluntary participation of participants in the study.

Regarding minorities, the National Institutes of Health (NIH) and Alcohol, Drug Abuse, and Mental Health Administration (ADMHA) specifically enacted policies requiring the inclusion of women and minorities in study populations (NIH, 1990; 1994). These policies are consistent with findings on the *under-representation of ethnic minorities* documented in the literature (Burlew, 2003).

Such official policies provide legal grounds to enforce fair research procedures. Yet, despite those governmental regulations, there are additional considerations necessary to implement sensitive research steps and make accurate methodological and analytical decisions. We next provide an overview of such considerations.

Demographic Overview of the Hispanic Population in the USA

Individuals with a Spanish origin or descent in the USA frequently are identified as Hispanic or Latino(a). Despite differences in meaning, both labels often are used interchangeably. *Hispanic*, a label derived from the Latin word 'Hispania' (Spain), is the official term coined to identify individuals of Spanish origin or descent. *Latino(a)* describes an origin from a Latin American country, including Portuguese-speaking Brazil and English-speaking Belize and the Guyanas (Marín & Marín, 1991). Nonetheless, as described later, because Hispanics or Latinos(as) in the USA represent a very diverse demographic profile, use of either label as an umbrella term can obscure specific differences among Hispanic/Latino(a) groups and among individuals in a Hispanic/Latino(a) group (also see Introduction to this volume for a related discussion). Particularly for research purposes, individual background characteristics need to be described.

The US Hispanic population is growing rapidly. Hispanics currently represent 42 million people or 14% of the total US population including both the continental territory and Puerto Rico (US Census Bureau, 2003). After African-Americans, Hispanics constitute the largest minority group in the US with an estimated increase to 25% of the overall population by 2050 (National Alliance for Hispanic Health, 2004). Moreover, important population trends among Hispanics have been reported (National Alliance for Hispanic Health, 2004). The Hispanic population is particularly young, with a median age of 25.8 years, compared with 38.6 years for non-Hispanics, and families are generally larger than among non-Hispanics in the USA. The majority of Hispanics are employed yet they are disproportionately likely to have low-paying uninsured jobs. Additionally, a high rate of high-school dropouts, at least since 1970, has also been reported for Hispanics.

Hispanics in the USA are a heterogeneous group who generally share language and aspects of Hispanic culture (Marín & Marín, 1991; National Alliance for Hispanic Health, 2004). They represent different countries of origin and varied educational and socioeconomic levels, and, linguistically speaking, a wide range of receptive and expressive skills in Spanish and English (Centeno & Obler, 2001; Roca & Lipsky, 1993; also see Introduction to this volume). As supported by the latest population reports, Mexican-Americans constitute the largest group followed by Central Americans and South Americans, Puerto Ricans, Cubans, and other Hispanics (US Census Bureau, 2002). In terms of annual earnings, Puerto Ricans are over-represented in the low-income bracket followed by Mexican-Americans, Cubans, Central and South Americans, and other Hispanics. Regarding educational attainments, Mexicans represent the largest group in the 'less than high school diploma' category followed by Central and South Americans, Puerto Ricans, and Cuban-Americans. Finally, regarding language, Hispanics employ a number of dialectal varieties of Spanish consistent with their countries and regions of origin. They also show different proficiency levels in Spanish and English, thus being identified as monolingual, when having minimal skills in either language, or bilingual, when having considerable skills in both languages (Centeno & Obler, 2001; Iglesias, 2002). Such discrepancies in socioeconomic, educational, and linguistic backgrounds among Hispanics need to be analyzed carefully when looking at each subgroup and individual because they have confounding effects on many other variables such as health risk, access to health care, and overall social achievements (Iglesias, 2002).

Cultural Factors in Research on Hispanic Populations

Characteristics of the target population must be understood for appropriate approaches to research and the collection of valid findings.

Particularly, formulation of the questions to be investigated, participant selection, research design, and data interpretation must realistically reflect the perspective of the individuals being studied (Burlew, 2003; Huer *et al.*, 2003; Kayser, 1995; Silverman, 1997).

Before turning to their ramifications for research, a number of culturally based characteristics of Hispanics in the USA need to be considered. It is important to bear in mind that the group or individual presence of these characteristics depends on a complex interaction of higher-level factors such as acculturation levels, generational factors, ancestry, and sociopolitical circumstances (Hidalgo, 1993; Matute-Bianchi, 1991; also see Brozgold & Centeno, ch. 5, this volume).

Acculturation refers to changes in the original culture experienced by an individual or group when contrasting cultural communities are in frequent contact (Marín *et al.*, 2003). Rather than being a unidimensional quantifiable phenomenon, acculturation involves multiple factors such as language preference, beliefs, group affiliation, gender roles, attitudes, and self-identity (Pontón, 2001b). Understanding the relationships, challenges, and outcomes in the interaction between ethnic identity formation and acculturation in minority–majority contexts is complex. Research has shown that both personal and societal factors need to be assessed as both minority group and individual separately experience their culture in the context of a larger majority society (Centeno, 2007; also see Brozgold & Centeno, ch. 5, this volume). Indeed, drawing from reports on Hispanics in the USA, cultural acceptance/rejection may vary according to gender, generation, urban versus rural locations, socio-economic circumstances, length of residence in the new country, and pressures from the majority society on the minority group and its members (see Hidalgo, 1993; Torres, 1997; Zentella, 1997).

For example, members of Hispanic groups who are born in the USA and are young tend to prefer English and more closely identify with American cultural values than foreign-born and older Hispanics (Matute-Bianchi, 1991; Zentella, 1997). Further, Hispanic individuals of any age may gravitate toward American norms, including the use of English, in situations of social pressure from the majority community (Hidalgo, 1993). Consequently, acculturation differences among Latinos(as) in the USA play an important role in defining heterogeneity within the group. Next, based on the extensive discussions provided by Marín and Marín (1991) and Pontón (2001a; 2001b), we summarize the most important variables pertinent to communication research on Hispanics, cautioning the reader to bear in mind that, due to acculturation levels, these factors may operate differently within the various Hispanic groups and its members.

Latinos(as) have been characterized as embracing certain attitudes in their social networks. Latino(a) communities tend to have a strong sense

of collectivism, or *allocentrism*, in which, rather than stressing individuals' needs, the group's needs and objectives are emphasized. At the family level, Hispanics similarly show a strong identification with, and attachment to, their nuclear and extended families. This cultural phenomenon, labeled as *familialism* or *familism* (Marín & Marín, 1991), tends to involve strong loyalty and solidarity among members of the same family. Additionally, Hispanics also emphasize smooth and pleasant social interactions, or *simpatía*, hence showing empathy with the feelings of other people, minimizing conflict, and showing respect to others (Marín & Marín, 1991).

Distance – both metaphoric and literal – is another cultural phenomenon in Hispanic groups that requires attention. At a larger social level, power differentials play a role in determining the distance among individuals by promoting deference and respect toward certain groups or individuals (e.g. the rich, the educated, the aged). During conversation, Hispanic individuals have been shown to prefer shorter physical distances with their interlocutors than non-Hispanics do. Relative to non-Hispanics in the USA, Hispanics tend to have a flexible attitude to *time*, which often translates into being late for appointments or the misperception of length of time spent on tasks. Such a flexible orientation to time allows Hispanics to feel they are on time, even when they arrive late to an appointment by others' cultural norms (Marín & Marín, 1991).

Like all cultures, Hispanics have defined gender-related behaviors for both men and women. Cultural expectations for men relate to being strong, in control, as well as providers, protectors, and representatives of their families (*machismo*). In contrast, women have traditionally been viewed as caregivers devoted to the well-being and nurture of their family and living in sacred duty, self-sacrifice, and chastity; roles often associated with the special place that the Virgin Mary has in the largely Catholic Latin American culture (*marianism*) (Gil & Vazquez, 1996). Of course, not all Hispanics subscribe to these culturally stereotypic gender roles. In fact, as described later, because societal attitudes toward minority groups are generally based on stereotypes, researchers must be cautious with the possible effects of implicit attitudes and stereotyping on research with minorities (Khan, 2003.)

Finally, cultural phenomena in Hispanics in the USA cannot be examined without considering the concomitant linguistic heterogeneity in the group. As mentioned earlier in this section and elaborated on elsewhere in this book (see Anderson & Centeno, ch. 1, Brozgold & Centeno, ch. 5, and Centeno, Ch. 3, this volume), Hispanic individuals in the USA show considerable linguistic variability, representing different dialects of Spanish and varying degrees of proficiency in Spanish and English (Centeno & Obler, 2001; Iglesias, 2002). Such a linguistic scenario

is a critical component when examining acculturation patterns and diversity in this community.

As with any participants in research studies, Hispanics' routine culturally determined behaviors and attitudes are likely to have an impact on their disposition, performance, and outcomes during clinical research investigations. We continue with a discussion of possible implications of the above cultural dynamics on the procedures employed in speech-language pathology research with Hispanic individuals.

Methodological Aspects in Research with Hispanic Speakers

Participant issues

Participants selected for research must be representative of the target group for valid and accurate generalization of the findings (Glattke, 2002; Mertens, 1998). An operational definition specifying the inclusion criteria used to identify the intended group of study is necessary. As described above, the Hispanic population in the USA is very diverse. On one hand, different levels of acculturation need to be understood. When differentiating among Hispanics, it is important to distinguish between race and ethnicity. While the former is a biologically determined condition resulting in physical characteristics, the latter is a complex psychoemotional phenomenon involving the interaction of acculturation levels, self-identity, language preference, social networks, and lifestyles (Marín & Marín, 1991; Mertens, 1998). In fact, in the last national census, Hispanics identified themselves with a variety of race categories, including white, Black or African-American, American Indian, Alaska Native, and Asian (US Census Bureau, 2000). On the other hand, other factors, such as different levels of bilingualism, countries of origins, and socioeconomic background, add to Hispanics' within-group heterogeneity. Yet, there are three ways Hispanic ethnicity may be operationalized: ancestry, cultural characteristics, and self-identification (Marín & Marín, 1991).

Once the target Hispanic participants have been defined, access to, recruitment, and retention of the sample follow (Burlew, 2003; Hammer, 2000; Huer *et al.*, 2003; Marín & Marín, 1991). Discussion of the numerous strategies suggested to minimize difficulties throughout such sampling steps in ethnic minorities is beyond this chapter. Most notably, minority individuals' healthy skepticism towards research and their resulting limited participation can effectively be addressed when the investigator becomes familiar with the community, establishes direct contact with potential participants, explains the legitimacy and benefits of the study to the group, obtains the sponsorship of local organizations and leaders, and provides compensation for participation in the study (Burlew, 2003; Hammer, 2000; Huer *et al.*, 2003; Marín & Marín, 1991).

The influence of cultural factors on the motivation, disposition, and interpersonal dynamics of Hispanic research participants deserves special attention. *Simpatía* may encourage an initial promise from the individuals to participate in the study which they may not fulfill later. Routine interactions with Hispanics who stand closer to the investigator may be misinterpreted by an investigator who is unfamiliar with the culture. On the other hand, the participant may perceive the investigator's need for more space as distant and cold, which may translate into feelings of exploitation. Additionally, as mentioned above, a flexible orientation to time may encourage Hispanics to feel they are on time even when they arrive late to their appointed times (see Marín & Marín, 1991, for an extensive discussion).

Measurement issues

Bias-free research in a multicultural environment requires instrument content, design, and administration to reflect the cultural assumptions, knowledge, and behaviors of the research participants (Bravo, 2003; Kayser, 1995; Marín & Marín, 1991). Differences in performance may not reflect a deficit but a culturally determined effect (Silverman, 1997). Particularly, measurement tools employed with ethnic minorities have to be grounded in realistic experiential, linguistic, socioeconomic, and metric principles if accurate cross-culture comparisons are to be made and realistic evidence-based clinical procedures are to be developed for the target group (Bravo, 2003; Kayser, 1995; Marín & Marín, 1991).

Linguistic content, behavioral requirements for administration, and numerical information to be obtained warrant special attention. Participants' linguistic background, be it monolingual Spanish or bilingual Spanish-English, as well as language stimuli, critically vocabulary and sentence structures, must be reflected in the stimuli and instructions used (also see Anderson, ch. 9, Anderson & Centeno, ch. 1, Centeno, ch. 3, Restrepo & Castilla, ch. 10, this volume for relevant discussions). In addition, behavioral test demands and familiarity with the test format may be in opposition to the individuals' typical routines (Bravo, 2003). For instance, a task measuring reaction time may yield inaccurate results if Hispanic research participants, based on a flexible attitude to time, provide pensive, articulate, and delayed responses to questions or other stimuli (Glattke, 2002). Additionally, some research contexts (e.g. interviews) might be seen as social occasions, rather than time-restricted sessions, by some Hispanics hence requiring the investigators to extend the length of the research activity to include social time (Huer *et al.*, 2003). Finally, if task administration employs the collection of scores, researchers must be aware of certain psychometric factors, such as available norms and content validity, that may not include or apply to the minority group in the study (Glattke, 2002; Marín & Marín, 1991).

Data interpretation issues

A number of cultural factors may have an impact on the participants' performance on tasks and, in turn, the validity of the data collected (Silverman, 1997). Marín and Marín (1991) discuss how some typical patterns in Hispanic culture, previously covered in this chapter, may affect the process and outcomes in a given study. For example, a tendency to favor respectful, nonconflictive interpersonal interactions may motivate Hispanic individuals to produce extreme, socially desirable, or acquiescent responses, or *yea-saying*, hence showing a tendency to agree in their answers. Similarly, the power/distance principle may result in exaggerated deference – by non-Hispanic standards – that Hispanic respondents may show for a researcher who comes from outside the community; a phenomenon requiring careful management to avoid extreme agreement responses during interviews. Such situations promoting extreme answers in Hispanic research participants warrant attention. These response trends impact data analysis and interpretation in a way that affects group variance and score correlations. In fact, investigators analyzing data obtained from Hispanics should examine actual score distributions rather than focusing on measures of central tendency as extreme response sets may provide inaccurate descriptions of a group's responses if only measures of central tendency are considered (Marín & Marín, 1991).

There is evidence suggesting over-reporting and under-reporting behaviors among Hispanics, like other minorities, in relating to investigators from outside the community, particularly when questions involve threatening or sensitive information. Based on an analysis of Hispanic informants' responses to health surveys, Aday *et al.* (1980) suggest that, relative to non-Hispanics in the USA, Hispanic individuals favored socially desirable responses hence over-reporting in their answers, and had a greater proportion of unanswered questions than non-Hispanics resulting in the under-reporting of information and incomplete data. Further, Hispanics may be more likely to under-report in situations of self-disclosure of personal information, such as talking about money, tastes, or when cultural gender dynamics make it difficult for the informant to speak freely to investigators of the opposite sex (Huer *et al.*, 2003; LeVine & Franco, 1981; Marín & Marín, 1991). Although there is limited evidence on such behaviors, researchers should exercise caution when administering instruments dealing with sensitive information to Hispanic research participants.

Future Directions

This chapter provided an overview of ethical, demographic, and cultural factors critical to the planning and implementation of clinical

communication studies with Hispanics in the USA. Our discussion highlighted some special areas of concern relevant to participant selection and the collection of valid findings. Such logistical and methodological challenges can effectively be addressed with strategies grounded in the sound understanding of the different normative factors in Hispanic groups. Central to the research process is the realistic knowledge of typical cultural dynamics and their application throughout the conceptual, methodological, and analytical steps of the clinical communication study. Because working with Hispanic research participants, like other CLD populations, is complex, application of interdisciplinary research approaches should be helpful to enhance accuracy in the methods employed in clinical communication studies. For example, the use of acculturation measures, used in neuropsychological research (e.g. Pontón, 2001b), and multiple assessments of language identification and usage, used in sociolinguistic and neurolinguistic studies of child and adult bilingualism (e.g. De Houwer, 1995; Paradis, 2004; Torres, 1997; also see Centeno, ch. 3, this volume), would be useful tools to complement the existing battery employed in clinical communication investigations. The preceding instruments and methods would provide excellent complementary information to select and classify research participants, create appropriate tasks and stimuli, and interpret results.

Thus, training researchers to have in-depth knowledge of the different phenomena that impact communication skills in the heterogeneous Hispanic population in the USA is necessary. As Hispanics in the USA steadily increase in both numbers and diversity, the need for valid and accurate research to develop appropriate evidence-based clinical procedures for this population is imperative. Yet, in addition to the theoretical knowledge, such research must be grounded in appropriate ethical principles respecting Hispanic individuals' lives and considering their complex backgrounds. The principles discussed here, although primarily based on Hispanics in the USA, can be adapted to the unique sociocultural and linguistic contexts of Hispanic persons in other countries.

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