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Characterization of the Hispanic or Latino Population in Health Research: A Systematic Review

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Abstract

The size and diversity of the Hispanic population in the United States has dramatically increased, with vast implications for health research. We conducted a systematic review of the characterization of the Hispanic population in health research and described its implications. Relevant studies were identified by searches of PubMed, Embase Scopus, and Science/Social Sciences Citation Index from 2000 to 2011. 131 articles met criteria. 56 % of the articles reported only “Hispanic” or “Latino” as the characteristic of the Hispanic research population while no other characteristics were reported. 29 % of the articles reported language, 27 % detailed country of origin and 2 % provided the breakdown of race. There is great inconsistency in reported characteristics of Hispanics in health research. The lack of detailed characterization of this population ultimately creates roadblocks in translating evidence into practice when providing care to the large and increasingly diverse Hispanic population in the US.

Keywords

Hispanic population; Population characterization; Health research; Ethnicity

Background

In the past decade, the size and diversity of the Hispanic or Latino population in the United States has increased dramatically. In the 2010 Census, approximately 50.5 million people in the US, or 16.3 % of the total US population, identified their ethnicity as Hispanic or Latino, a 43 % increase from the 2000 Census [1]. During the past decade, the growth in the US Hispanic population accounted for more than half (53 %) of the country's population growth [2]. 18 million of these Latinos are immigrants, an increase of more than 4 million since the year 2000 [3].

Currently, the federal Office of Management and Budget (OMB) specifies just two choices in the category of ethnicity for use in federal data collection: “Hispanic or Latino” and “Non-Hispanic or Latino” [4]. OMB defines Hispanic or Latino as, “a person of Cuban, Mexican, Puerto Rican, Cuban, South or Central American, or other Spanish culture or origin, regardless of race [4].” These ethnicity categories are also used in health research and are captured in large datasets. Asking individuals to identify their ethnicity as Hispanic or Latino or Non-Hispanic or Latino has become a standard part of demographic data-gathering. It is a question, though, that relies on language and other common traditions to group individuals of Hispanic or Latino origin. But not everyone who fits these criteria identifies themselves first and foremost as Hispanics or Latinos. Many Hispanics or Latinos in the United States tend to self identify more often with their country of origin or with their ancestors' country of origin, and provide that information as their ethnicity. The US Census Bureau has taken note of this and has included “Puerto Rican,” “Mexican, Mexican–American, Chicano,” and “Cuban” as subcategories of the Hispanic or Latino ethnicity choice for the previous two decennial censuses (2000 and 2010). In this review, we use Hispanic or Latino interchangeably for reading clarity, mindful of the fact that members of this population may choose to self-identify as one or the other.

The Hispanic population in the US is far from monolithic. Collectively, those who identify themselves as Hispanic or Latino have immigrated or have ancestry from more than 20 countries and territories, speak more than six different languages, and fall all along the socioeconomic spectrum [5–7]. The majority of Hispanics in the US live in large metropolitan areas, including cities in California, New York, Florida, and Arizona [2]. However, of note, the states with the largest percentage increase of the Hispanic population during the past decade include Alabama, Arkansas, Kentucky, Mississippi, North Carolina, Tennessee, South Carolina, Maryland, and South Dakota [2]. Historically, these states had relatively small Hispanic populations, and they have had to quickly adapt to the needs of their growing Latino groups.

Those needs include addressing the health disparities that exist within this large and increasingly diverse population. Some of these disparities may seem to be associated with factors related to country or region of origin and other demographic variables [8–11].

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Lawsin et al. [8] found that length of stay in the United States was significantly associated with breast and cervical cancer knowledge and rates of breast self exam. Pabon-Nau et al. [9] found that diabetes and hypertension prevalence among Hispanics vary by country or region of origin, with Puerto Ricans having a higher rate of hypertension and Puerto Ricans and Dominicans having a higher rate of diabetes compared to Hispanics from other countries of origin. In addition, a growing body of evidence suggests that some health disparities that exist in the Hispanic population may be undetectable if only ethnicity (Latino/Hispanic) is used as the defining characteristic of the population, but visible when looking at specific demographic characteristics like language(s) spoken, US or foreign-born, and number of years in the United States, among others [12–17]. Oliveira et al. [12] found that Hispanics, whose primary language was Spanish, had a significantly higher rate of late stage breast cancer diagnosis than those who reported English as their primary language.

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Federal, state, and local institutions have included some of these characteristics when collecting data from the population. For example, in 2009 the Massachusetts Department of Public Health in their “Massachusetts Births report” found that of all births among Hispanic mothers, 5.5 % were teen births. This rate was higher for specific Hispanic population, taking into account their country/territory of birth. For instance, within Puerto Ricans in Massachusetts, the percentage of teen births was 8.1 %. A similar difference was found when looking at low birth weight, where 8.6 % of births among Hispanics were considered low birth weight, but the percentage was higher for births among mothers from Puerto Rico and the Dominican Republic (12 and 8.7 % respectively) [18]. The New York City Department of Health and Mental Hygiene, in its 2006 report on the Health of Immigrants in New York City, highlighted the importance of obtaining and reporting further characteristics of the Latino population. Based on data collected through the NYC Community Health Survey, the report found that years living in the United States, primary language, and country of origin play a role in rates of HIV, obesity, and diabetes, among others, in this populations [19].

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Not surprisingly, within the US Hispanic population, as in virtually all populations, an individual's resources, including education, income, and language proficiency, can greatly influence access to care, treatment, and health outcomes. A report by the Pew Hispanic Center, for example, found that Hispanics who are born abroad, speak mainly Spanish, and who have been in the US for a relatively short time are less likely to have a regular source of medical care than their US-born, mostly English-speaking, counterparts [20]. In addition, a study by Downs et al. [21] of disparities in the incidence of, and mortality rates from, cervical cancer found an association between low socioeconomic status, limited English proficiency, and being foreign-born, and Latinas' cervical cancer screening and treatment disparities.

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It is, therefore, crucial for researchers and providers to take into account the varied and distinct demographic characteristics that exist within the Hispanic population. The Institute of Medicine's (IOM) Subcommittee on Standardized Collection of Race/Ethnicity Data for Healthcare Quality Improvement recognized this in its 2009 report. The report noted that while analyses of data, that include the OMB's race and ethnicity categories, “can reveal important disparities in care...more discrete population data are needed to identify

opportunities for quality improvement and outreach without inefficiently targeting interventions to an entire broad race or Hispanic ethnicity category [22].” Citing the “strong evidence that the quality of health care varies as a function of race, ethnicity, and language,” the report went on to recommend that patient data collection not only include the existing OMB race and ethnicity categories, but also granular ethnicity (so named because it encompasses more detailed or “fine-grained” categories of ethnicity, based on ancestry), spoken English proficiency, and preferred spoken language [22]. In October 2011, the US Department of Human Health Services (HHS) also recognized this need when it proposed new guidelines that require more fine-tuned criteria in health research [23]. In congruence with the Affordable Care Act, the newly set HHS standards will include the collection of race, ethnicity, gender, primary language, and disability status in all new surveys and major revisions to current surveys. One of the most pertinent changes to the survey standards is to refrain from using broad, umbrella terms, for instance, “Hispanic” or “Latino” [23]. The goal is to collect data that are as specific as possible, are at the least geographical level, to improve understanding of racial or ethnic subgroups. The more refined criteria will help to elucidate the many disparities that exist in health care, especially those between and within major ethnic groups such as Hispanics/Latinos, thereby facilitating measurement and intervention design in the near future.

Despite the evidence that suggests that a more detailed characterization of Hispanic/Latino populations would be helpful to those engaged in the provision of health services and in the development of health policy, the literature does not reflect this, limiting the applicability of its evidence. While some researchers choose to obtain and record more detailed information than ethnicity for Hispanics, such as country of origin, US or foreign-born, languages spoken, and number of years of residence in the US, many others do not. The effect of inconsistent or absent standards in reporting characteristics of Hispanic research populations is the homogenization of a highly heterogeneous group. Treating a Hispanic study population as uniform has the potential to negatively impact the applicability of research findings, the delivery of needed care, and ultimately, health outcomes. To assess and document the extent of this variation, we undertook a systematic review of all papers published between 2000 and 2010 that specifically examined ethnicity and colorectal cancer, particularly in the areas of screening and prevention, diagnosis, and treatment.

We chose to focus our review on colorectal cancer (CRC) for several reasons. The first is that effective CRC screening requires patients to adhere to a complicated set of instructions and steps; adherence with CRC screening recommendations may be influenced by language and other related factors to a greater extent than screenings for other diseases [24]. The second reason, which in all likelihood is correlated with the first, is that disparities have been observed in the Hispanic population in every aspect of the disease, from screening rates to cancer stage at diagnosis to mortality rates [25, 26]. According to the American Cancer Society's Cancer Prevention & Early Detection Facts & Figures 2011, only 37.2 % of Hispanics living in the US were up to date with CRC screening compared to 56 % of the white, non-Hispanic population; foreign-born Hispanics have lower rates of CRC screening and prevention than those who were born in the US [27]. Although these data show that there are major differences in CRC screening in this population, a more detailed description of the population is rarely provided or used for analysis. Third, CRC could be seen as a

crossover issue between multiple specialty areas in medicine including primary care, gastroenterology, oncology, and surgery. Fourth, CRC is preventable with timely screening, potentially saving thousands of lives [28]. Finally, cancer disparities may serve as a marker for greater disparities found in the continuum of care of many other conditions, because necessary points of cancer care include prevention, screening, timely treatment completion, survivorship services, and end of life care.

Methods

A comprehensive search of electronic databases was conducted, including PubMed, Embase Scopus, and Science Citation Index/Social Sciences Citation Index for peer-reviewed articles in English that included at least one keyword related to the Hispanic population and one keyword related to colorectal cancer. We chose these databases based on their prevalent usage by the numerous specialties that provide evidence related to Hispanics and colorectal cancer (i.e. Social sciences, Behavioral Sciences, Biology). For the first category, search terms included “race,” “ethnicity,” “heritage,” “Latino,” “Hispanic,” “Immigrant,” “Migration,” “Foreign Born,” and “newcomer.” The second category including search terms such as: “colorectal cancer,” “colon cancer,” “rectal cancer,” “rectum cancer,” “colon and rectum cancer,” “colon and rectal cancer,” and “gastrointestinal cancer.” Articles were considered if at least one key term relating to the population of interest and one key term relating to colorectal cancer appeared anywhere in the document. The reference list for each retrieved article was also searched, but produced no additional articles for consideration. Based on these keywords, we identified 253 potential articles for review (Fig. 1).

After reviewing the abstracts of these articles, we selected for final inclusion those that met the following criteria: (1) the article's aims/objectives included ethnicity and colorectal cancer, (2) the article reported Hispanics or Latinos in the results, and (3) the Hispanic population in the article was living in the US.

A total of 131 articles met our criteria described above. We reviewed the full text of each selected article and tabulated the following information: specific aims/objectives of each article and the characteristics of the Hispanic population, which the article's authors reported or used for analysis (see Table 1) [24–26, 29–156].

To describe the focus of the articles included in the study, we categorized them based on their specific aims/objectives. Thirty randomly selected articles were reviewed by two independent coders to generate a list of brief categories that represented the underlying aims of the articles. After each coder completed his/her list of categories, they met to reach agreement and develop a consensus list of categories. A second set of 30 randomly selected articles was obtained, and independent coders applied the list of categories to this set of articles. Inter-coder reliability was measured using Cohen's Kappa. Percentage of agreement between coders was 95 % and coefficient kappa was 0.83. Finally, coders applied this list of categories to the rest of the articles included in this review (see Table 2).

Results

131 articles were included in the study. An average of 1.7 Hispanic population characteristics were reported (median: 1, min. 1, max. 5) and included ethnicity, race, immigration history (country of origin, years in the United States), and language. Forty percent of the articles reviewed reported only “Hispanic” as the characteristic for the Hispanic research population and 16 % reported only “Latino” while no other characteristics for the population were reported. Thirty-eight (29 %) of the articles reported the languages spoken by the Hispanics in their study population. Thirty-five (27 %) of the articles detailed whether the Hispanic population in the study was US or foreign-born. Twenty-one (60 %) of these articles focused on Hispanic immigrant populations as their main study population. Of the 35 articles that reported whether study participants were born in the US or abroad, approximately half (17) described the most common countries of origin for their study population and 6 (17 %) of those reported the number of years each foreign-born participant had lived in the United States.

Thirty articles included information on race for their populations studied; of those, only 3 provided the breakdown of race characteristics specifically for their Hispanic study populations (Hispanic plus race). The other 27 articles equated Hispanic (ethnicity) with racial categories. None of these articles reported the criteria used to allocate Hispanic participants who may have self-described their race as White or Black or Asian to either the Hispanic group (ethnicity) or to one of the racial groups.

Of the 131 articles included in this review, 62 used primary data collection, 64 used pre-existing data for their analysis (secondary data analysis), and 5 were reviews of the current literature or meta-analyses. On average, those articles that collected primary data reported 1.92 characteristics of their Hispanic study population. Those articles that used secondary analysis on average reported 1.38 characteristics and the review articles reported, on average, 1.40 characteristics of their Hispanic study population. The distribution of the number of characteristics reported across all studies included in this review was not normally distributed (Shapiro–Wilk test of Normality, $p < 0.0001$), therefore using Kruskal–Wallis test for independent samples we found a statistically significant difference in the number of reported characteristics based on source of reported data ($p < 0.0001$).

Table 2 shows the ten categories created and used to group all 131 articles included in the analysis; the same table presents data on the number of Hispanic population characteristics reported within each category. Following the method described above, two coders created the following categories: (1) biological, physiological, genetics, (2) cost-effectiveness, (3) CRC incidence, prevalence, treatment and survival disparities, (4) CRC screening disparities, (5) evaluation of CRC screening tests, (6) intervention evaluation, (7) practices, attitudes and behaviors towards CRC screening, (8) predictors for CRC screening, (9) quality of life (QOL), and (10) risk factors for CRC.

We found that the articles categorized as addressing issues in the areas of Intervention Evaluation, Practices, and Attitudes and Behaviors towards CRC Screening reported the most granulation (means 2.1 and 2.3 respectively). Articles addressing issues in Quality of

Life and Cost-Effectiveness reported on average the fewest number of characteristics (mean: 1). Using non-parametric analysis, due to the non-normal distribution of the number of characteristics reported, we found a statistically significant difference in the number of characteristics reported between categories (Median test: $p = 0.003$, Kruskal–Wallis test: $p = 0.002$), as well as a significant association between categories and number of characteristics reported (Spearman: $p < 0.0001$).

Discussion

As this focused review of the literature demonstrates, there is a great inconsistency in the reported characteristics of Hispanics in health research. In addition, many authors do not include more granular characterizations of Hispanic study participants beyond ethnicity (an incomplete and very limited depiction) and rarely provide an explanation as to why they chose not to obtain additional information and how such omissions might limit their findings. This inconsistency is further evident when such articles are categorized based on their objectives. Furthermore, we found significant differences in the number of characteristics reported dependent on the source of the data used for the article's analysis. Although articles that used primary data collection reported significantly more characteristics of the Hispanic population, perhaps showing a pitfall of secondary data analysis, the average was just below 2 per article (one of those being ethnicity, Hispanic/Latino). This, in our view, is insufficient to describe the Hispanic population, particularly when authors had the potential to modify their methods to include, report, and analyze this information.

Several reports have been released in the previous years suggesting that a more detailed characterization of this population, beyond ethnicity alone, could lead to more precise research findings, which, in turn, could lead to more targeted intervention strategies, better health policies, and better health outcomes [22, 157]. While the Office of Management & Budget (OMB) statistical policy Directive number 15, which specifies the minimum race and ethnicity categories to be used by federal programs in data collection, states that “these classifications should not be interpreted as being scientific or anthropological in nature [4],” health researchers have nonetheless used the categories of ethnicity and race described in the Directive to characterize their study populations for more than three decades. Many researchers have even ignored the Directive's stipulation that the question of ethnicity (Hispanic and Non-Hispanic) be asked separately from that of race. Hispanics may self-identify as being of any race, and data have shown that in the US, for example, more than half of Hispanics identify themselves as white [2]. Even so, in the literature it is common to see race and ethnicity conflated in the characterization of the study population. Participants may be characterized, for example, as “White,” “African-American,” or “Hispanic.” Indeed, in our review of the CRC literature, the vast majority (27 out of 30) of papers that reported race did not break down the Hispanic population by race, and in many instances, comparisons were made between Hispanics or Latinos and racial groups such as White, African-American, or Asian. Furthermore, none of these articles provided an explanation as to what criteria were used to categorize the study population in this manner, and whether, for example, a “White-Hispanic” participant, “Black-Hispanic” participant, or Asian-Hispanic participant was characterized as “White,” “Black,” “Asian,” or “Hispanic.”

Researchers should also be aware that in addition to the racial categories proposed by the US Federal government through OMB Directive No. [154], there are other categories that are widely used in Latin American countries and are accepted by their governments as official racial classifications, such as Mestizo/mixed race, Mulatto, and Zambo (Black descendant). We believe these categories may be more familiar to certain segments of the Hispanic or Latino population in the United States than the racial categories adopted by Directive 15. Depending on the population to be studied, we encourage researchers to consider the possibility of including these, or other racial categories, that may be common in their study population. We believe that increasing the precision of the racial variable will only help to increase the reliability of the information provided by study participants, which will in turn ensure the accuracy of the research findings and ultimately assist practitioners in better implementing the scientific evidence produced by the research.

In addition to race, English proficiency varies within the Hispanic population in the US. Approximately 70 % of the Hispanic population in the US speak a language other than English at home and 33 % report speaking English less than very well [158]. Limited English proficiency (LEP) can adversely affect health services access and health outcomes [159, 160]. LEP is noticeably higher among foreign-born Hispanics [158]. Cheng et al. [161] found that Hispanics who spoke a language other than English at home were at higher risk for not obtaining recommended health care services, and concluded that collecting language information in the Hispanic population should be imperative when intervening to improve health outcomes. Therefore, we strongly encourage researchers to inquire about their study populations' native languages and to report those results.

Approximately 18 million Hispanics in the US are foreign born and almost 13 million of them are non-US citizens [3]. Hispanic immigrants come from over 20 countries [3] and there are significant differences in health needs and health outcomes among them. For example, according to Pabon-Nau et al. [9], the prevalence of hypertension and diabetes varies significantly among Hispanics by country of origin, and concludes that health research should assess this characteristic and include representation from all Hispanic subgroups to provide applicable findings.

Additional to country of origin, it is important for researchers to ascertain study participants' length of stay in the US. For example, the Personal Responsibility and Work Opportunity Reconciliation Act of 1996 [162] bars immigrants who have been in the US for less than 5 years from accessing many entitlement programs, including health care insurance programs. Because this can greatly affect new immigrants' access to care, we believe it is necessary to obtain length of stay information from Hispanic study participants to better understand the health outcomes observed and to adapt any health care intervention designed.

Several studies in the broader literature have found the importance of this level of characterization. For instance, Latino immigrants reported better Oral Health-Related Quality of Life, but this effect disappeared in the subsequent generations. Chang et al. found that country of origin and acculturation, among other factors, modified gastric cancer incidence among Hispanic populations and Jacobs et al. found that the use of interpreters did not increase hospital costs, but, in fact, reduced return ED visits and overall costs. By

detailing study results by more granular population characteristics, results can be more appropriately applied, thus providing the full benefit of the research findings.

The lack of detailed characterization of the Hispanic research subjects can ultimately create roadblocks in translating evidence into practice when providing care to the large and increasingly diverse Hispanic population in the US. This review highlights the need to account for multiple variables, including at least race, ethnicity, country of origin, language, years in the US, and socioeconomic status to provide accurate interpretation of health indicators and helpful information in translational research. However, this is not current practice. While accurate interpretation of health indicators is certainly fundamental to translating evidence into practice, to improve the adaptation, dissemination, and adoption of evidence-based interventions, health researchers must change their data collection methodology to include at a minimum the variables described above. The adoption of a new set of characterization standards beyond ethnicity will serve as an important foundational step to overcoming the many health disparities existing in the Hispanic population in the United States.

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Fig. 1. Inclusion flowchart

Table 1
Number of publications reporting each characteristic of the Hispanic or Latino population

Variable(s) reported/used for analysis	Number of publications reporting these variable(s) n = 131
Hispanic	53
Latino	21
Hispanic or Latino	2
Hispanic or Latino—US born versus Foreign born	5
Hispanic or Latino—US born versus Foreign born—years in US	1
Hispanic or Latino—US born versus Foreign born—years in US—language (Spanish only) ^d	1
Hispanic or Latino—US born versus Foreign born—country of origin	5
Hispanic or Latino—US born versus Foreign born—country of origin—years in the US	1
Hispanic or Latino—US born versus Foreign born—country of origin—years in US—language (Spanish or English)	2
Hispanic or Latino—US born versus Foreign born—country of origin—language (Spanish or English)	5
Hispanic or Latino—US born versus Foreign born—country of origin—language (Spanish only)	3
Hispanic or Latino—US born versus Foreign born—language (Spanish or English)	6
Hispanic or Latino—language (Spanish, English or other)	5
Hispanic or Latino—language (Spanish only)	5
Hispanic or Latino—language (English only) ^b	2
Hispanic or Latino—language other ^c	1
Hispanic or Latino plus race ^d	1
Hispanic or Latino plus race—US born versus Foreign born—country of origin—language (Spanish only)	1
Hispanic or Latino plus race—Language (Spanish or English)	1
Hispanic or Latino—Mexican American—US born versus Foreign born—language (Spanish or English)	2
Hispanic or Latino—Mexican American—language (Spanish or English)	1
Hispanic or Latino—Mexican American subgroup	1
Mexican American—US born versus Foreign born—language (English only)	2
Puerto Rican and Dominican—years in the US—language (Spanish or English)	1
Hispanics grouped as non-white	3

^a Only Spanish was reported, or only Spanish speakers were included

^b Only English proficiency was reported

^c Non English speakers were included but no report of specific languages

^d Race is describe for those Identified as Hispanic or Latinos, using the Office of Management and Budget (OMB) classification

Table 2
Article categories and number of characteristics reported

Categories	Number of articles	Number of Latino population characteristics reported		
		Mean	Median	Range (min, max)
Biological, physiological, genetics ^a	14	1.3	1	(1, 3)
Cost-effectiveness ^b	3	1	1	(1, 1)
CRC incidence, prevalence, treatment and survival disparities ^c	29	1.2	1	(1, 3)
CRC screening disparities ^d	16	1.9	1	(1, 4)
Evaluation of CRC screening test ^e	5	1	1	(1, 1)
Intervention evaluation ^f	20	2.1	2	(1, 5)
Practices, attitudes and behaviors towards CRC screening ^g	20	2.3	2	(1, 5)
Predictors for CRC screening ^h	18	2	2	(1, 4)
QOL ⁱ	2	1	1	(1, 1)
Risk factors for CRC ^j	4	1.75	1	(1, 4)

CRC colorectal cancer, QOL quality of life

^aRefs.: [42, 44, 49, 60, 68, 70, 87, 89, 106, 107, 116, 135, 140, 141]

^bRefs: [86, 94, 130]

^cRefs: [23, 24, 28–30, 45, 51, 71, 72, 76–78, 98, 103, 109–111, 117, 127–129, 131, 132, 138, 139, 142, 146, 147, 153]

^dRefs: [33, 34, 36, 40, 57, 67, 69, 83, 95, 97, 102, 118, 122, 148, 149, 152]

^eRefs: [55, 85, 105, 126, 130]

^fRefs: [43, 46, 52, 66, 73, 74, 79, 80, 88, 90, 92, 99–101, 104, 108, 114, 136, 143, 154]

^gRefs: [27, 31, 35, 38, 39, 41, 47, 48, 50, 54, 58, 59, 61, 63, 81, 82, 84, 91, 115, 144]

^hRefs: [22, 32, 37, 53, 56, 64, 75, 93, 96, 112, 113, 119–121, 124, 134, 150, 151]

ⁱRefs: [123, 125]

^jRefs: [62, 65, 133, 137]