Received: 17 August 2020 | Revised: 29 September 2020 | Accepted: 1 October 2020

DOI: 10.1002/jgc4.1351

National Society of Genetic Counselors | WILEY

BRIEF REPORT

State of recent literature on communication about cancer genetic testing among Latinx populations

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Funding information
National Cancer Institute's Behavioral Research Program, Grant/Award Number: HHSN261201700078P; Huntsman Cancer Foundation; U.S. Department of Health and Human Services

Abstract

Cancer-related genetic testing (hereafter CGT) has transformed cancer prevention, treatment, and care. Researchers debate whether diffusion and use of genetic testing will reduce or widen cancer health disparities through effects on improving or worsening cancer-related mortality, morbidity, and outcomes that disproportionately affect racial and ethnic minority populations. Cancer disparities by race and ethnicity have been associated with social determinants of health and healthcare access and experience. However, little research has explored how communication about CGT may contribute to these disparities. As such, the goal of this study was to characterize the literature published between 2010 and 2017 on communication about CGT among Latinx populations through a secondary analysis of papers identified in a larger scoping review. We found thirteen (2.5%) of 513 papers in the parent scoping review had over 50% Latinx representation; only nine of these (69%) had fully Latinx comprised study cohorts. The majority of the 13 identified studies ($n = 9$) were conducted to assess knowledge and attitudes regarding CGT. Most studies included services or materials in both Spanish and English. Few studies assessed language preference or acculturation or compared outcomes across sub-ethnicities. We identified opportunities for researchers to explore differences in outcomes by language preference and acculturation, and between sub-ethnicities in future studies. Leveraging a greater understanding of the heterogeneity within the Latinx population will allow genetics researchers and providers to improve utilization of CGT and therein health outcomes to advance health equity.

KEYWORDS

cancer, communication, disparities, genetic testing, Latinx/Latino, scoping review

1 | INTRODUCTION

Cancer genetic testing (CGT) has transformed cancer prevention, treatment, and care (Kensler et al., 2016). Researchers have debated whether diffusion and use of genetic testing will reduce or widen cancer health disparities through effects on improving or worsening cancer-related mortality, morbidity, and outcomes that disproportionately affect racial and ethnic minority populations (Smith et al., 2016). Data have shown that while genetic testing has been instrumental for identification and clinical management of individuals with inherited cancers, racial and ethnic minority populations are not benefiting from testing and improved health outcomes at the same rates as White populations (Halbert & Harrison, 2018). These disparities in access to and outcomes of genetic testing by race and

ethnicity have been linked to social determinants of health (e.g., socioeconomic status, education level, discrimination, segregation) and healthcare access and experiences (Canedo et al., 2019; Galea et al., 2011; Moy & Freeman, 2014). In order to further understand the mechanisms underlying these disparities, the current analysis aimed to describe the recent research on communication about CGT with Latinx populations by conducting a secondary analysis of papers that were identified through a parent scoping review on communication about CGT (Kaphingst et al., 2019).

Latinx is the gender-neutral term for Latino/a and refers to any individuals with origins from Latin America (Aragones et al., 2014). Although not a homogeneous population, Latinx members share language and aspects of history and, as such, are typically combined into a single category for research studies (Aragones et al., 2014; Cruz-Correa et al., 2017). Previous research has found Latinx utilization of CGT to be lower than Whites (Cruz-Correa et al., 2017). A recent national study found that the *BRCA1/2* genetic testing rate among Latina women was 18% compared to 30% for White women (Levy et al., 2011). Another study related to colorectal cancer found a CGT rate of 3.1% for Latinx individuals compared to 10.7% for non-Hispanic Whites (Hall et al., 2012). These findings are consistent with the theory of Diffusion of Innovation, which describes how newer technologies and services often are distributed unevenly with racial and ethnic minority groups having access later than those more socially privileged (Rogers, 2003).

While disparities in use of genetic testing have been documented for various cancers (e.g., breast, colorectal, liver) (Canedo et al., 2019; Kinney et al., 2010; Levy et al., 2011; Pagán et al., 2009), potential explanations of these testing disparities have varied, including lack of awareness, associated costs, low levels of interest, adverse psychological consequences, and limited health literacy (Canedo et al., 2019; Cruz-Correa et al., 2017; Kinney et al., 2010; Sussner et al., 2013). Even when offered CGT related to Lynch syndrome and hereditary breast and ovarian cancer, Latinx populations are less likely to test (Butrick et al., 2015; Hall et al., 2012; Muller et al., 2018). Prior empirical research related to CGT has suggested that the uneven distribution of testing may be due to both individual-level factors (i.e., awareness, knowledge, attitudes) (Bloss et al., 2018; Kinney et al., 2010; Pagán et al., 2009; Singer et al., 2004) and system-level factors (i.e., insurance, access, trust) (Peters et al., 2004; Roberts et al., 2019; Singer et al., 2004). As system-level factors, prior research has found that primary care physicians that serve minority (and indeed non-minority) populations tend to have less knowledge of specialized topics (i.e., genetics) and may be less likely to refer patients to genetic counseling and testing (Armstrong et al., 2005; Haga et al., 2019; Hauser et al., 2018; Shields et al., 2008). As primary care providers may not feel knowledgeable about this technology, unless they have had a personalized genetic testing experience, they often do not refer their patients to testing (Haga et al., 2019). Canedo et al. (2019) completed a systematic review of genetic testing among different racial/ethnic subgroups and found that Black and Latinx populations had significantly more concerns about genetic testing if they were aware of it, but often they were unaware of genetic testing. Other studies have found that lack of awareness is one of the largest barriers to testing among Latinx populations (Canedo et al., 2019; Cruz-Correa et al., 2017; Levy et al., 2011).

What is known about this topic

Latinx populations have higher morbidity and mortality from certain cancers and lower utilization of screening such as genetic testing.

What this paper adds to the topic

This study is the first to characterize the state of recent literature on communication about cancer genetic testing among Latinx populations. We identified opportunities for researchers to explore differences in outcomes by language preference and acculturation, and between subethnicities, in future studies to better inform delivery of cancer genetic services to these populations.

Communication about CGT likely affects differences in awareness and utilization of this testing. Kinney et al. (2006) found that primary care physicians discussed *BRCA1/2* genetic testing significantly less with Latina women compared to White women (Kinney et al., 2006). Despite this initial finding, the research on communication about CGT with Latinx patients and communities has not been well characterized. The current analysis reviewed seven years of published papers that had a majority of participants who were Latinx. These papers were initially identified through a parent scoping review, which was conducted to characterize research on communication about CGT as a whole (Kaphingst et al., 2019). The goals of the present analysis were to describe the state of this communication literature focused on Latinx communities and identify opportunities to enhance communication with Latinx communities about CGT.

The parent scoping review (Kaphingst et al., 2019) utilized the Preferred Reporting Items for Systematic Reviews and Meta-Analysis (PRISMA) guidelines (Moher et al., 2009). A literature review of six databases identified English-language articles related to communication about CGT with patients and the general public published between January 2010 and January 2017 (Kaphingst et al., 2019). Broad search terms included cancer, genetic/genomic, communication, provider/direct-to-consumer, and patient/public. The scoping review characterized general study information, outcomes or themes, cancer and genetic focus, participant characteristics, and the return of results process. The present analysis focused on those identified studies with a majority (i.e., over 50%) Latinx participants based on the study's definition of Latinx, consistent with the parent scoping review. For the studies meeting this inclusion criterion, we assessed definition of Latinx, study design, language(s) utilized, genetic services offered (genetic testing and counseling were offered

to participants), outcomes, group comparisons (if applicable), and key findings.

Thirteen (2.5%) of the 513 papers in the parent scoping review had over 50% Latinx representation; only nine of the 13 papers (69%) had fully Latinx comprised study cohorts. The studies focused on a wide range of research questions, including baseline knowledge and attitudes toward CGT, process of communication about CGT, and how test results were returned and communicated to clients. The majority of the 13 identified studies ($n = 9$) were conducted to assess knowledge and attitudes regarding CGT (Table 1). Qualitative and quantitative designs were used equally, with five studies having a mixed methods design. Most of the studies ($n = 9$) had psychosocial outcomes as the main type of outcome. For study locations, seven of the 13 studies were situated in United States (U.S.) coastal cities (i.e., New York, Burbank, Tampa), three in Texas, two in the Intermountain West (Salt Lake City and Albuquerque), and one study was conducted outside the United States, in Cuba.

Definitions of Latinx varied among the studies. Eleven studies used self-reporting to identify Latinx participants while the other two used language (Spanish fluency) or geographic location (Cuba) as a proxy for Latinx identity. Ten of the 11 studies utilizing self-report did not formally define Latinx in their methods section. Only five of the 13 studies overall defined Latinx or Hispanic, generally in the introduction. Country of origin and Spanish-language preference were also used as proxies for characterizing Latinx identity with four of the 13 studies using these variables as groupings in comparisons (i.e., sub-group ethnicity, language preference). Only two studies (15%) assessed acculturation and compared CGT rates by acculturation level. In the nine studies fully comprised of Latinx participants, only two (20%), both by Vadaparampil et al., 2010 and 2011, compared sub-ethnicities within Latinx communities (i.e., Puerto Rican, Cuban, Mexican). Among the four studies that included participants from different racial and ethnic groups (e.g., Black, Asian), none compared Latinx sub-ethnicities.

The distribution of language preference varied across studies, ranging from 20% to 60% of participants having a preference for Spanish compared to English. In examining the language in which genetic services were offered, we found that most of the studies ($n = 10$) provided the research materials (i.e., genetic services, printed marketing materials, educational materials, questionnaires, interview and focus group protocols) in both English and Spanish, while three used only Spanish. Of the studies fully comprised of Latinx participants, all nine offered services and/or research protocols and materials in English and Spanish by bilingual service providers or research staff. Six of the 13 studies (46%) had genetic counselors delivering services, in each there was at least one bilingual genetic counselor for non-English-speaking clients. The remaining studies had research staff delivering research materials and/or services (e.g., skin cancer materials translation, individual interview/focus group facilitation) in either English or Spanish, dependent upon the study population and outcomes of interest for the study. It was unclear if research staff delivering these research materials and/or services were credentialed in genetics but to our interpretation they appeared to be knowledgeable regarding the topic. However, a lack of genetic credentials of research staff that are bilingual may contribute to lower utilization of CGT among Latinx members.

Our study is the first to characterize published research on communication about CGT focused on Latinx populations. The findings from this analysis show that there is a critical need for greater research focused on Latinx communities within this literature. From 2010 to 2017, only 13 of more than 500 published studies on communication about CGT had a majority of participants who were Latinx, and even fewer assessed sub-ethnicities. We found the published research in this area used both qualitative and quantitative methods. The most common research focus was assessment of knowledge and attitudes about CGT, and the studies had primarily psychosocial outcomes. Although examination of these outcomes is crucial to the advancement of engagement with Latinx populations, there were few studies assessing behavioral outcomes of CGT, highlighting a gap in the literature. Additionally, only six studies offered genetic services delivered by genetic counselors, highlighting another gap of limited implementation studies conducted with Latinx populations. As a strength of this literature, we found bilingual language offerings common, which is likely to broaden recruitment efforts. However, few studies compared sub-ethnicity characteristics like language preference that could influence CGT outcomes. These findings therefore highlight gaps in the literature on communication about CGT and opportunities for future research.

Often Latinx communities are treated like a homogeneous population in health research (Aragones et al., 2014). However, with the variety of Latin American cultures, demographic characteristics, and ancestral origins, Latinx communities are highly heterogeneous. This is a common challenge in health research with Latinx populations, as often definitions of *Latinidad* (Latinness) are reliant on self-identification as Latino/Hispanic or not; this type of designation, however, can lose predictive power when aggregated. Keeping the definition of Latinx broad can improve recruitment (Aragones et al., 2014) while adhering to the U.S. federal definition of Hispanic/Latinx as an ethnic background distinct from race (U. S. Census Bureau, 2020). Ethnic origin relates generally to a social definition recognized in this country rather than biological, anthropological, or genetic criteria (U. S. Census Bureau, 2020). However, use of other variables such as language preference, acculturation, and sub-ethnicity demographics within the broad Latinx categorization allows better characterization of the heterogeneity within this population and warrants further exploration.

In this analysis, we identified an opportunity for greater examination of language preference. The reviewed studies presented findings and implications regardless of the language in which services, outcomes, or research protocols were delivered. While language preference may not play a role in all outcomes related to communication about CGT, additional investigation of differences in outcomes or effect modification by language preference is needed. The potential importance of language preference for intervention design has been recognized in terms of overall intervention success (Wilkin et al., 2007). We recommend that

TABLE 1 Study characteristics of reviewed articles

Author(s)/Year/Site	Definition of Latinx	Main Outcomes	Genetic Services Offered?	Methodology	Language(s)	Group Comparison	Key Findings
Chalela et al., 2012/ Hidalgo County, TX, USA	Latina Women	Psychosocial (Knowledge, Attitudes, behavioral intention to CGT)	No	Qualitative Interviews	English & Spanish	Level of Education	Key Latino values of religiosity, family, and influence of healthcare providers play an important role in awareness and attitudes toward CGT[1] and should be considered in designing interventions
Gibbon, 2011/Cuba	Cuban women	Psychosocial (genetic knowledge, identify, and family)	No	Ethnography & Qualitative Interviews	Spanish	Cuban Regions	Cuban healthcare institutions still face challenges of misinformation or misunderstandings of cancer diagnoses and genetic testing results contexts with Cuban women patients
Kinney et al., 2010/Salt Lake City, UT, USA	General eligibility requirement included identifying oneself as Hispanic or Latino	Psychosocial (Attitudes, beliefs and communication preferences of CGT)	No	Qualitative Interviews	English & Spanish	Level of Education, Sex, and Community Leadership Roles	Latinx members have low awareness of CGT and its benefits. CGT communication efforts should utilize bilingual media and cultural perspectives to improve access and implementation
Kukafka et al., 2015/New York City, NY, USA	Hispanic (self-reported), English-speaking Women	Decision Making	No	Mixed Methods (Quantitative & Qualitative)	English	Race & Numeracy	The web-based decision aid, RealRisks, improved perceived breast cancer risk, but barriers remained including distrust of healthcare systems, uncertainty of results, and access to care
MacDonald et al., 2012/ Burbank, CA, USA	Eligible invitees were Latinos with a personal or family history of breast or ovarian cancers	Psychosocial, Process of CGT Communication, Return of Results Outcomes	Yes	Mixed Methods (Quantitative & Qualitative)	Spanish	CGT Patients versus Non-patients	Following return of CGT results, Latina women should include informational and psychosocial support using patient/family centered conferences to address disparities in CGT engagement
Mette et al., 2016/South Texas, USA	Patients were of Hispanic background	Process of CGT Communication	Yes	Quantitative	English & Spanish	Race, SES, Education, Age	Through a developed video-teleconferencing risk assessment and consulting of CGT, the intervention was noted as an acceptable method of providing cancer risk assessment for remote and underserved populations
Rodríguez et al., 2017/ Albuquerque, NM, USA	Spanish fluency and Spanish- reference	Psychosocial (Knowledge and understanding of Skin Cancer risk materials)	No	Qualitative Interviews (Cognitive Interviews)	Spanish	Education Level & Materials reviewed	Spanish translated skin cancer genomic risk education materials (SOMBRA) were successful in improving awareness and perceived risk by Latinx participants.
Sussner et al., 2015 (a)/ New York City, NY, USA	Women self-identifying as Latina	Psychosocial (Knowledge, Attitudes, Acculturation)	Yes	Mixed Methods (Quantitative & Qualitative)	English & Spanish	Age, History of Cancer, Interview Format	Personal and community awareness of CGT was low for all participants. Main motivations for CGT were concerns of learning about family members' cancer status with the main barrier being competing demands. Younger Latinx women were more interested in CGT compared to older Latinx women

(Continues)

TABLE 1 (Continued)

Author(s)/Year/Site	Definition of Latinx	Main Outcomes	Genetic Services Offered?	Methodology	Language(s)	Group Comparison	Key Findings
Sussner et al., 2010 (b)/ New York City, NY, USA	Women self-identifying as Hispanic/Latina	Psychosocial (Interests and beliefs of CGT)	Yes	Mixed Methods (Quantitative & Qualitative)	English & Spanish (participant preference)	Individual Interview versus Focus Group	Despite low awareness and knowledge of CGT, Latina women reported interest in the technology. Culturally tailored education materials including narratives may increase knowledge and contribute to improving CGT engagement
Sussner et al., 2013 (c)/ New York City, NY, USA	Women who self-identified as Latinas	Psychosocial (Barriers, Facilitators, Interest, Beliefs of CGT)	Yes	Quantitative Telephone Interviews	English & Spanish	Age, History of Cancer, Interview Format	Educational interventions are needed to promote BRCA genetic counseling among at-risk Latinas and promote referrals from physicians by discussing perceived barriers
Vadaparampil et al., 2010 (a)/Tampa, FL, USA	Hispanic women who self-identified as Mexican, Puerto Rican, or Cuban.	Psychosocial (Knowledge and Attitudes toward CGT)	No	Mixed Methods (Quantitative & Qualitative)	English & Spanish (participant preference)	Sub-ethnicity (Mexican, Puerto Rican and Cuban)	All participants with a personal/family history of breast cancer have similar rates of awareness of their risk, knowledge of and concerns of CGT. However, Cuban women wanted more messages of urgency with results compared to Mexican and Puerto Rican women. Cuban and Mexican women also held more fatalistic attitudes toward CGT results compared to Puerto Rican women. These sub-ethnic differences should be further explored and used in genetic counseling settings
Vadaparampil et al., 2011 (b)/Tampa, FL, USA & Puerto Rico	Eligible participants were self-identifying Puerto Rican women residing in Tampa or Puerto Rico	Psychosocial (Knowledge and Attitudes)	No	Mixed Methods (Quantitative & Qualitative)	Unclear (English appeared to be the language used)	Puerto Rican Women living in Puerto Rico versus in Tampa, FL	All participants were interested in receiving CGT for breast cancer noting that the best facilitator to them would be their provider's recommendation, but commonly cited the barrier of cost. Improving recruitment by eliminating costs can improve Latinx CGT engagement
Woodson et al., 2015/ Houston, TX, USA	Self-reported demographics (Hispanic)	Decision Making & Return of Results Outcomes	Yes	Quantitative	English & Spanish	CGT Patients versus Non-patients	Through retrospective electronic health record review, a group-counseling model was most success in engaging racial/ethnic participants, but lack of transportation, limited patient knowledge of family cancer history, and language barriers remain challenges in delivering CGT care. A long-term genetic clinic in a community hospital with group-counseling is recommended to improve CGT engagement

Abbreviations: CGT, cancer genetic testing; SOMBRA, The Skin Health Online for Melanoma: Better Risk Assessment.

language preference should be assessed within Latinx comprised cohorts with reporting of whether or not differences in outcomes are observed by language preference, especially if bilingual materials are offered.

We found only two studies that assessed acculturation, highlighting another important gap in the literature on communication about CGT. In one example, Sussner et al. (2015) compared interest in CGT by acculturation. Language preference has historically been used as a proxy for acculturation, until the latter began to emerge as a separate predictor for psychosocial and health outcomes (Schwartz et al., 2010). Recent research has found that more acculturated Latinx youth generally are more receptive to using technological innovations compared to those who are less acculturated (Landry et al., 2015), suggesting that acculturation may impact utilization of CGT. More generally, utilization of novel technologies has been characterized as a benefit of biculturalism (belonging to two distinct cultures) and acculturation (Benet-Martínez & Haritatos, 2005), both of which have been noted to contribute to better psychosocial well-being and health outcomes compared to those who are monocultural or less acculturated (Coatsworth et al., 2005). While the research on communication about CGT has utilized few measures of acculturation, greater use of such measures could have implications for research and practice. It is important to provide culturally tailored and appropriate materials to Latinx patients (Hann et al., 2017). Acculturation measures could be one way of helping those developing genetic communication materials for Latinx patients (Vadaparampil et al., 2006). For example, materials and services might be tailored in terms of the most appropriate language or platform for delivery (e.g., mobile phones, *Telenovelas*, Spanish-language radio). Leveraging knowledge of acculturation and language preference could enhance the ability of genetics researchers and providers to diffuse CGT more broadly and encourage participation in future studies.

While acculturation and language preference capture some key characteristics of a Latinx participant, it is also important for researchers to study Latinx populations by sub-ethnicity. Only two studies in our review from the same research team compared sub-ethnicities (Vadaparampil et al., 2010, 2011). The lack of detailed characterization of the heterogeneity within Latinx populations (e.g., values, beliefs, language) will likely lead to barriers and delays in translating clinical care and policies to the broader population (Aragones et al., 2014). Prior research indicates that health disparities within Latinx communities may go undetected if ethnicity (Latino/Hispanic) is the only demographic characteristic assessed (Chen et al., 2011; Eamranond et al., 2009; Keegan et al., 2010; Pinheiro et al., 2011). As efforts continue, it will be essential to compare Latinx sub-ethnicities to better understand how differences between communities influence awareness of, access to, and use of CGT. For example, data suggest that Cuban and Puerto Rican women are more aware of, have greater access to, and utilize CGT to a greater extent than those of Mexican origin (Cruz-Correa et al., 2017). The Institute of Medicine and Department of Health and Human Services have noted the importance of characterizing Latinx individuals in research beyond ethnicity; nativity, language preference, acculturation, number of years in the United States, and sub-ethnicity all may uncover health disparities and contribute to a better understanding of disparities within and between population subgroups (Institute of Medicine, 2009; U.S., Department of Health, & Human Services, 2015).

Despite our novel findings, the analysis is not without limitations. Our analysis focused on papers published from 2010 to 2017, and there may have been additional research completed outside this timeframe. Because few studies have been conducted with Latinx populations, we could not conduct a meta-analysis or generate effect sizes. Finally, we only included studies published in English, so there is the possibility of Spanish-language published research on communication about CGT. Despite these limitations, this analysis is the first to characterize the lack of Latinx representation in the literature on communication about CGT. Greater community engagement and partnerships with community-based organizations may improve participation in research studies through inclusive language and messaging and outreach through appropriate platforms. We also recommend that researchers highlight language preference differences, assess acculturation, and compare outcomes within sub-ethnicities in future studies as part of efforts to improve access to CGT among Latinx populations. With a more robust understanding of the heterogeneity within the Latinx population, researchers, genetics providers and counselors, and policymakers can improve utilization of CGT and therein health outcomes to advance health equity.

AUTHOR CONTRIBUTIONS

DCY and KK substantially contributed to the conception or design of the work; or the acquisition, analysis, or interpretation of data for the work. DCY, WYSC, and KK drafted the work or revised it critically for important intellectual content. DCY, WYSC, and KK approved the final version to be published. DCY, WYSC, and KK agreed to be accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved.

ACKNOWLEDGEMENTS

Financial support was provided by the National Cancer Institute's Behavioral Research Program through HHSN261201700078P. We also acknowledge the direct financial support for the research reported in this publication provided by the Huntsman Cancer Foundation. The opinions expressed by the authors are their own and this material should not be interpreted as representing the official viewpoint of the U.S. Department of Health and Human Services, the National Institutes of Health or the National Cancer Institute.

COMPLIANCE WITH ETHICAL STANDARDS

CONFLICT OF INTEREST

Daniel Chavez-Yenter, Wen-Ying Sylvia Chou, and Kimberly A. Kaphingst declare that they have no conflict of interests.

Human Studies and Informed Consent

No human subjects were involved with this research study.

Animal studies

No non-human animal studies were carried out with this study.

DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available from the corresponding author upon reasonable request.

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How to cite this article: Chavez-Yenter D, Chou W-YS, Kaphingst KA. State of recent literature on communication about cancer genetic testing among Latinx populations. *J Genet Couns*. 2020;00:1–8. https://doi.org/10.1002/jgc4.1351