J Genet Counsel (2017) 26:379–386
DOI 10.1007/s10897-016-0051-x

REVIEW PAPER

Clinical Cancer Genetics Disparities among Latinos

Marcia Cruz-Correa[1,2] · Julyann Pérez-Mayoral[1,2] · Julie Dutil[3] · Miguel Echenique[4] · Rafael Mosquera[5] · Keila Rivera-Román[6] · Sharee Umpierre[1] · Segundo Rodriguez-Quilichini[1] · Maria Gonzalez-Pons[1,2] · Myrta I. Olivera[1,2] · Sherly Pardo[7] · on behalf of the Puerto Rico Clinical Cancer Genetics Consortia

Received: 7 July 2016 / Accepted: 16 November 2016 / Published online: 12 December 2016

Abstract The three major hereditary cancer syndromes in Latinos (Hereditary Breast and Ovarian Cancer, Familial Adenomatous Polyposis and Lynch Syndrome) have been shown to exhibit geographic disparities by country of origin suggesting admixture-based disparities. A solid infrastructure of clinical genetics geared towards diagnosis and prevention could aid in reducing the mortality of these cancer syndromes in Latinos. Currently, clinical cancer genetic services in Latin America are scarce. Moreover, limited studies have investigated the mutational spectrum of these cancer syndromes in Latinos resulting in gaps in personalized medicine affecting diagnosis, treatment and prevention. The following commentary discusses available genotype and clinical information on hereditary cancer in Latinos and highlights the limited access for cancer genetic services in Latin America including barriers to genetic testing and alternatives for providing better access to genetic services. In this review, we discuss the status of clinical genetic cancer services for both US Latinos and those Latinos living in Latin America.

Keywords Genetic testing · Genetic counseling · Health disparities · Hereditary cancer · Hispanics

✉ Marcia Cruz-Correa
marcia.cruz1@upr.edu

on behalf of the Puerto Rico Clinical Cancer Genetics Consortia

[1] Division of Cancer Biology, University of Puerto Rico Comprehensive Cancer Center, PMB711 Ave. De Diego 89 Ste. 105, San Juan, PR 00927-6346, USA

[2] Department of Medicine, University of Puerto Rico School of Medicine, San Juan, PR, USA

[3] Ponce Research Institute, Ponce Health Sciences University, Ponce, PR, USA

[4] Cancer Center, Auxilio Mutuo Hospital, San Juan, PR, USA

[5] Puerto Rico Gastroenterology Association, San Juan, PR, USA

[6] Department of Pediatrics, University of Puerto Rico School of Medicine, San Juan, PR, USA

[7] Department of Pathology, University of Puerto Rico School of Medicine, San Juan, PR, USA

Introduction

"Hispanics" or "Latinos" (henceforth named Latinos) are a diverse group of individuals that share a common language and history. Due to the colonization process that occurred in Latin America, Latinos are a mix of European, African and Native American populations. Each of these ancestral populations have contributed differently, depending on the local history, the degree of slave trade in the area, and the genetic background of each Latino subpopulation (Avena et al. 2012). According to the latest United States (US) census, 16.3% of the US population identified themselves as Latino (Bureau 2013). The Latino population of the US is expected to grow exponentially, reaching 25% of the total US population by 2050. Thus, disparities in access to appropriate health care, including access to cancer genetic services, and health literacy among Latinos may have significant impact on the burden of cancer diagnosis in US Hispanics. In this review, we discuss the status of clinical genetic cancer services for both US Latinos and those Latinos living in Latin America. We also review barriers for cancer genetic testing in these underserved Latino populations.

Cancer in Latinos

Approximately 126,000 new cases of cancer occurred in 2015 in Latinos (Siegel et al. 2015). Even though the incidence and mortality rates for Latinos in the US are lower than in non-Hispanic Whites (NHW) (Siegel et al. 2015), there is a notable increase in the incidence rates for US Latinos when compared to their country of origin. Furthermore, Latinos are more likely to present at advanced disease stages when compared to their NHW counterparts (Pinheiro et al. 2009). Three of the major cancers affecting Latinos are breast (29%), prostate (22%), and colorectal cancers (11% for males and 8% for women). All of these cancers are known to have a genetic component (Siegel et al. 2015). These cancers have different incidences and mortality rates depending on the country of origin of the Latino individual. For example, incidence rates of the cancers mentioned above are lower in Mexicans compared to Puerto Ricans and Cubans (Siegel et al. 2015). The differences observed among Latino subpopulations might be due to differences in the genetic background of the population, and socioeconomic and environmental differences, including access to cancer screening and prevention services across Latin America.

Hereditary Cancers in Latinos

Latinos present with differences in the mutational spectrum of hereditary cancer syndromes, such as Hereditary Breast and Ovarian Cancer (HBOC) and Lynch Syndrome (LS). For HBOC, the mutation profile in the *BRCA1/2* genes varies according to the Latino subpopulation (Dutil et al. 2015). Caribbean Latinos, such as Puerto Ricans and Cubans, have a higher prevalence of mutations in the *BRCA2* gene (Dutil et al. 2012; Rodriguez et al. 2008); whereas, Latinos from Mexico have mutations more frequently in *BRCA1* (Weitzel et al. 2005). Similarly, LS patients from Puerto Rico present more frequently with *MSH2* mutations, compared to other Latino subpopulations or NHW (Cruz-Correa et al. 2015). The data obtained from these studies suggest that the mutation spectrum of hereditary cancer syndromes is different and diverse among Latinos. Further studies are needed to comprehensively characterize hereditary cancer syndromes among Latinos.

Clinical Cancer Genetics for US Latinos

Several studies have focused on understanding the disparities observed in genetic testing for Latinos in the US using a variety of measures, which we discuss in this section:

Acculturation and Awareness of Genetic Testing

Studies have reported on the level of awareness of genetic testing in Latinos and the impact of acculturation and education on awareness about genetic testing. These studies have been performed mostly in US Latinas with hereditary breast cancer. Several reports have consistently shown that US Latinos and immigrants have lower awareness of genetic testing (Gammon et al. 2011; Honda 2003; Pagan et al. 2009; Ramirez et al. 2006; Sussner et al. 2015; Suther and Kiros 2009; Vadaparampil et al. 2006). Furthermore, the level of awareness has been shown to differ across US Latino subpopulations, with Puerto Ricans having the highest level of awareness of genetic testing, compared to Mexicans and Cubans (Vadaparampil et al. 2006). In an additional study, knowledge of genetic testing was shown to not differ significantly between Puerto Ricans living in Tampa and Puerto Rican living in Puerto Rico, suggesting access to cancer genetic services might be key to disparities observed between the two groups (Vadaparampil et al. 2011).

Awareness of genetic testing is also influenced by educational level, access to health care services and lifestyle/socioeconomic factors. Highly educated Latinos were 45% more likely to be aware of genetic testing than Latinos with less than high school education (Pagan et al. 2009; Vadaparampil et al. 2006). Furthermore, Latina women across all ethnic groups were unable to fully or partially explain genetic testing when asked (Vadaparampil et al. 2010a). Test awareness was higher among Latinos who saw or talked with a health professional within the last year, and for Latinos with military or private health insurance compared with individuals with public or no health insurance (Vadaparampil et al. 2006).

In addition to the factors discussed above, acculturation is an important element that influences awareness and knowledge of genetic testing in US Latinos. Acculturation has been associated with increased level of cancer genetic testing awareness among Latinos (Pagan et al. 2009; Sussner et al. 2009). English proficiency as a measure of acculturation was shown to be associated with increased awareness among Latinos (Heck et al. 2008; Vadaparampil et al. 2006). For example, 34.8% of Latinos who have English language proficiency knew about cancer genetic testing, compared to 18.4% in Latinos with intermediate use of English and 9.5% in Latinos with low use of English (Vadaparampil et al. 2006). Residence in the US for less than 5 years was associated with lower awareness of cancer genetic testing (Heck et al. 2008). Moreover, Latinos born in the US were 2-times more likely to know about cancer genetic tests than those Latinos who were foreign born (Vadaparampil et al. 2006). Generational differences among Latinas have been shown to influence awareness of cancer genetic testing, with younger Latinas (<55 years of age) being more interested in education about genetic counseling and cancer prevention than older Latinas (Sussner et al. 2015). Thus, education and acculturation have important roles in the awareness of Latinos about genetic counseling and testing for cancer.

Interest and Preferences for Genetic Testing among US Latinos

Several studies have looked at the interest of patients in obtaining genetic testing and counseling services in Latino populations with mostly positive results. Latinas have reported positive attitudes and interest in cancer genetic testing and counseling (Sussner et al. 2015; Sussner et al. 2010, 2013). This is consistent with reports that up to 82% of Latinas are interested in undergoing genetic testing once they understand the potential benefits of the test (Levy et al. 2011; Ramirez et al. 2006; Vadaparampil et al. 2010a). Furthermore, interest and participation of Latinas was positively associated with the amount of physicians' knowledge of clinical cancer genetics (Ricker et al. 2006).

A study evaluating preferences for receiving information on cancer risk demonstrated differences across US Latinos. When asked about their preference regarding the types of recommendation on cancer risk provided through genetic counseling, Mexicans showed a preference for messages that put their risk in the context of a group (Vadaparampil et al. 2010). Cubans preferred a message that showed urgency to get tested based on their risk, whereas Puerto Ricans had no preferred method. Similarly, there were differences across the three Latino subpopulations with regards to the type of information they would like to receive during genetic counseling. Cubans preferred information about the risks and benefits of the test, while Mexicans desired details about the actual procedures, and Puerto Ricans preferred information about the accuracy of the test (Vadaparampil et al. 2010b). Differences in whether or not the interviewed Latinos would recommend genetic counseling to a friend were shown across Latino subgroups (Vadaparampil et al. 2010b). Puerto Rican Latinos would reinforce recommendations of the physician as the most important consideration to be taken into account for referring a friend to testing (Vadaparampil et al. 2010b). In contrast, Cubans would not recommend testing to a friend (due to fatalistic views on cancer), and Mexicans considered the importance of spirituality and religiosity in recommending genetic testing to a friend (Vadaparampil et al. 2010b). Findings of these investigations support tailoring of genetic counseling according to ethnic background and Latino subpopulation.

Barriers to Genetic Testing Identified for US Latinos

In addition to increasing availability and access to genetic testing services, there is a need to understand the barriers for undergoing genetic testing in Latino populations. The most cited barrier for genetic testing among Latinos is cost or out-of-pocket expenses for testing (Kinney et al. 2010; Sussner et al. 2010; Vadaparampil et al. 2010b; Vadaparampil et al. 2011). Several studies have identified additional barriers including, learning about future cancer risk, learning about family cancer risk, fear of testing, competing life concerns (taking care of family) and adverse psychological consequences (anxiety, stress, etc.) (Kinney et al. 2010; Sussner et al. 2010, 2013). In addition, 28% of Latinos have concerns about the misuse of the information obtained from genetic tests (Suther and Kiros 2009). An important barrier identified in Latinos, as well as, in Caucasians, is difficulties in understanding percentage risk format, supporting the need for presenting cancer risk information in a variety of formats (Eichmeyer et al. 2005). Differences in barriers to genetic testing have also been observed across Latino subpopulations (Vadaparampil et al. 2010b). Cubans mostly identified financial concerns as their main barrier to testing, whereas Mexicans reported lack of provider discussion, and Puerto Ricans reported fear of tests and lack of awareness (Vadaparampil et al. 2010b).

Latinas were more likely to have negative views about genetic testing compared to Blacks or Caucasian women (Thompson et al. 2003). However, with increased acculturation Latinas are less likely to report barriers to genetic testing (Jagsi et al. 2015; Ramirez et al. 2006; Sussner et al. 2009). Several studies have demonstrated the acceptability of and readiness for cancer genetic services in Latinas (Lagos et al. 2008; Ricker et al. 2006). These findings warrant an in-depth investigation of attitudes, knowledge, health literacy, and other factors that can be associated with barriers for genetic testing in US Latinos in order to decrease disparities in access to and use of genetic tests.

Clinical Cancer Genetics in Latin America

Medical genetic services in Latin America are mostly provided by the public sector, but the service is uneven and concentrated in affluent and urban areas. Most of these services are for the prevention of congenital abnormalities, with limited resources spent on genetic services geared towards cancer syndrome diagnosis and prevention. The cost of genetic testing in Latin America makes this service inaccessible to a great majority of the population. In this section, we discuss the status of genetic services in various countries of Latin America where information about these services is available.

Argentina

In Argentina, the health care system is composed of coexisting systems of social security and for- profit or private clinics (Penchaszadeh 2009). Public insurance in Argentina covers 48% of the population, 47% is covered by social security, and around 5% is covered by the private sector (Penchaszadeh 2013). There are approximately 40 clinics that provide clinical genetic services, mostly located in public hospitals (Penchaszadeh 2009). These genetic clinics are mainly

involved in understanding pediatric diseases and single-gene disorders in children, with very few services offered for adult-related diseases (Penchaszadeh 2009, 2013). Genetic services in Argentina are underused due to lack of regulation and poor access for low-income families (Penchaszadeh 2013). Furthermore, lack of physician knowledge has been a factor contributing to the limited clinical genetic services in the region (Penchaszadeh 2013). However, initiatives have been developed to increase the knowledge of genetics among health care professionals in the region (Barreiro et al. 2013).

Chile

Genetic counseling in Chile is not a recognized discipline and is mostly provided by physicians (Margarit et al. 2013). Furthermore, as of 2013, only one trained genetic counselor and 28 clinical geneticists were available in Chile (Margarit et al. 2013). Nine of the available clinics in Chile are located in Santiago, a major city which is home to the majority of the population (Penchaszadeh and Beiguelman 1998). Health care in Chile is provided in a two-tier system, with public insurance covering around 70% of the population, private insurance covering approximately 17% of the total population, with the remaining 13% being uninsured (Vargas and Poblete 2008). This divide causes a disparity in access to quality health care, including genetic services, for low-income families due to limited government funding for health care (Vargas and Poblete 2008). Genetic services centers provide genetic counseling, as well as cytogenetics, birth defects and cancer genetics (Penchaszadeh and Beiguelman 1998). Several key issues concerning genetic services barriers in the region have been identified including: shortage of experts, few local laboratories, lack of resources, and disparate quality control in clinical labs (Margarit et al. 2013). Efforts are underway to expand genetic services in Chile.

Cuba

In contrast to most countries in Latin America and the Caribbean, in Cuba clinical genetic services (for congenital defects mostly) were conceived in the design of their health care system. The Cuban National Center for Medical Genetics is supported by the World Health Organization and aims to promote health through genetic approaches (Penchaszadeh and Beiguelman 1998). Medical schools in Cuba offer at least 18 credits of clinical genetics courses, and genetics is taught within all clinical disciplines (Penchaszadeh and Beiguelman 1998). Genetic testing is included as primary care in the hospitals and clinics in Cuba with clear objectives supported by their government (Penchaszadeh 2000). However, most of these efforts are concentrated on diagnosing congenital defects and neonatal screening (Penchaszadeh and Beiguelman 1998). Genetic services for birth defects and neonatal care had reached up to 97% of the population by the year 2000, making this a successful clinical genetics program (Marcheco 2009). However, Cuba's fiscal situation has diminished the availability of additional genetic services, such as cancer genetics, on the island.

Ecuador

The advent of genetic services in Ecuador started in 1984, with the establishment of two genetic clinics in the cities of Quito and Guayaquil (Penchaszadeh and Beiguelman 1998). In these two cities, two hospitals and one university are involved in genetics research, clinical genetic services and counseling (Penchaszadeh and Beiguelman 1998). Ecuador has a small number of professionals who specialize in genetics (Gonzalez-Andrade and Lopez-Pulles 2010). These professionals offer their services in small private medical centers mostly in big cities, where the majority of individuals in rural areas do not have access (Gonzalez-Andrade and Lopez-Pulles 2010). Demand for genetic services in Ecuador is limited, mostly due to lack of knowledge of the population (Penchaszadeh and Beiguelman 1998). In addition, Ecuador has limited availability of cancer genetic laboratories and regulatory procedures (Gonzalez-Andrade and Lopez-Pulles 2010).

Colombia

Medical genetic services in Colombia are offered at large medical schools and universities distributed among nine major cities of the country (Giraldo 2004). However, their degree of development varies. Furthermore, there is limited access to genetic testing since testing it is not covered by health insurance in Colombia (Giraldo 2004). Medical genetics training was established in Colombia during the 1960s (Penchaszadeh and Beiguelman 1998). Even though teaching of genetics in Colombia is mandatory, the offerings and topics covered are uneven across schools (Giraldo 2004). In Colombia, there are no clinical guidelines for cancer genetic testing (Penchaszadeh and Beiguelman 1998).

Brazil

Brazil's health care system is a universal public access system covering 80% of the population (Castilla and Luquetti 2009; Penchaszadeh and Beiguelman 1998). Genetic services are well-established and are offered in 64 genetic services centers, half of which are public and covered by the health care system (Castilla and Luquetti 2009). These genetic services include networks for study of inborn errors of metabolism, craniofacial abnormalities and cancer genetics (Castilla and Luquetti 2009; Penchaszadeh and Beiguelman 1998). However, most of the population does not have access to these services due to

a lack of government regulation of health services in Brazil (Horovitz et al. 2013). Approximately 30% of clinical genetic services are offered by professionals in the field (Horovitz et al. 2013). Brazil has a well-established Society of Medical Genetics, that has recognized more than 7 residencies in different hospitals across Brazil (Castilla and Luquetti 2009). Brazil has less than 300 clinical geneticists, a relatively small number given Brazil's population. The Brazilian government supports research projects in basic research for prevention and care strategies for Brazilians (Castilla and Luquetti 2009).

Mexico

Mexico's Society of Human Genetics was established in 1968 (Penchaszadeh and Beiguelman 1998). Since then, genetic professionals have joined and have established genetics curricula in medical schools (Penchaszadeh and Beiguelman 1998). There are approximately 20 hospitals offering genetic counseling and testing in Mexico (Penchaszadeh and Beiguelman 1998). However, due to the expensive cost of clinical cancer genetic tests, access to these services is very limited (Penchaszadeh and Beiguelman 1998). Furthermore, equipment and technology constraints negatively impact the reliability of results provided to the population (Penchaszadeh and Beiguelman 1998).

Venezuela

The medical core curricula of Venezuelan medical schools does not include significant training in medical genetics (Penchaszadeh and Beiguelman 1998). Most of the genetics clinics in Venezuela only provide very basic clinical and cytogenetic services. The demand for genetic testing services in Venezuela is strong. However, financial constraints and the political situation in Venezuela greatly limit the availability of these services.

Puerto Rico (Our perspective)

Medical genetic courses in Puerto Rico are offered at all levels of training including undergraduate and medical schools. Medical genetics is included in all medical schools on the island. In Puerto Rico, clinical genetic services are mainly offered in the city of San Juan. Most of the services provided are through the Pediatric University Hospital and are concentrated on diagnosing congenital defects, inborn errors of metabolism and craniofacial abnormalities. Clinical cancer genetic counseling is offered in a small number of clinics by trained physicians and is mainly limited to the largest cities of Puerto Rico. As a US territory Puerto Rico is covered by the Affordable Care Act (ACA) and Medicare, both of which recommend genetic testing for individuals at high-risk of hereditary cancer. Previous studies from our group have shown that at least 40% of individuals who qualified for genetic testing in Puerto Rico were denied coverage by their health insurance company (Cruz-Correa et al. 2015). However, these numbers are improving, thanks in part to research and education efforts of our medical community and collaborations with private health insurance companies.

Barriers to genetic testing identified for Latinos living in Latin America

Many barriers to widespread genetic services are cited, including: fragmented and inefficient health systems, deficient education in genetics for physicians, and lack of explicit policies to include genetics in health care (Penchaszadeh 2009). Barriers for genetic testing identified in Latin American cancer patients are similar to those identified in US Hispanics (Palmero et al. 2007). These barriers include: patients' lack of knowledge, difficulty accessing services and resistance of patients to seek genetic testing (Palmero et al. 2007). Additional studies are needed in all Latin American regions to better understand the unique barriers that affect genetic testing services.

Recommendations

Genetic testing services in Latin America have undergone expansion in recent years, but there are still many challenges to overcome if genetic testing is to be offered to the entire population. Because the public sector offers the majority of genetic testing services in Latin America, infrastructure, limited health policies and technology have a direct impact on the capacity to provide clinical cancer genetics services in these countries (Penchaszadeh 2015). The private sector usually offers services that are commercially profitable, such as paternity testing and prenatal diagnoses (Kofman-Alfaro and Penchaszadeh 2004). However, there is limited information regarding the quantity and quality of the clinical cancer genetic testing services offered by either the public or the private sector in Latin America. Based on our experience we propose the following recommendations to continue to promote access to clinical cancer genetics in Latin America.

1. *Training of Health Professionals in Genetic Testing and Counseling*

Trained professionals including medical geneticists and genetic counselors are limited in Latin America, and the services provided are concentrated in highly populated areas. The World Health Organization recommends that health authorities develop task forces of specialists in clinical, medical and

human genetics to aid in improving infrastructure, promote training of additional professionals, and aid in the integration of genetic services to existing health systems (Kofman-Alfaro and Penchaszadeh 2004). Furthermore, the WHO proposed that training in genetics be expanded to other health professionals including nurses, psychologists, health policy makers and epidemiologists at all levels of training (Kofman-Alfaro and Penchaszadeh 2004). Training on genetic testing and counseling should be expanded beyond congenital defects and neonatal screening to include genetic testing for hereditary cancers. Developing a critical mass of culturally diverse and culturally sensitive professionals is key to providing service to Latinos and is a priority to help decrease the gap in services across the US and Latin America.

2. *Educating the General Public about Genetic Counseling and Testing*

An important strategy to reduce disparities in access to genetic testing services is to educate the general public on the benefits of testing. It has been shown that Latinos have difficulties in understanding their genetic risks (Eichmeyer et al. 2005). Ethnic concordant educational programs aimed at improving knowledge of hereditary cancer and the benefits of genetic testing at the community level are warranted.

3. *Infrastructure Development*

Access to genetic services could improve in Latin America by integrating cancer genetic services into the robust health system infrastructure already in place, thus avoiding duplication of services and reducing cost (Penchaszadeh 2015). Implementation of public-private partnerships could circumvent the limited resources in the developing countries of Latin America. These public-private partnerships are used in other health care areas with great success and may improve access to genetic testing for low-resources populations. Furthermore, developing long-term sustainability plans and health policies are key to maintaining access to genetic testing and counseling.

To advance genetic services in Latin America, an influx of new technologies, especially for DNA sequencing is needed. However, until comprehensive knowledge of the mutation spectrum of the different cancer syndromes in Latinos is available, cost-effective and accessible gene testing alternatives will be limited. Next-generation sequencing (NGS) technologies could allow for extensive examination of multiple hereditary cancer syndromes. Additionally, NGS technologies will help to increase available knowledge about the prevalence and mutation spectrum of hereditary cancer in Latinos. NGS technology is currently used in clinical setting and may provide a cost-effective alternative for use in low-income clinical settings.

Conclusions

The evidence summarized above highlights the importance of proper access to genetic testing services for hereditary cancers in low-income communities across Latin America. Acquiring comprehensive knowledge about the mutation spectrum of hereditary cancers in Latinos is the first step towards improving access to genetic testing services. This would allow for multiple gene panels testing using NGS to be performed on a larger scale, which is cost-effective and could be accessible to a broader population. Furthermore, proper infrastructure, including integration of patient navigators and genetic counselors should be made available at regional clinics. This will increase participation in genetic testing and ensure that patients adhere to clinical guidelines established after testing positive or negative for mutations. Finally, education about genetic counseling and testing for hereditary cancers should be provided to health care providers and to patients. Engaging communities and organizations can aid in educating the general public about the benefits of genetic testing. The limited knowledge of genetic testing combined with limited economic resources can significantly reduce access to cancer genetic testing among Latinos, leading to a major health disparity among this population.

Acknowledgements This work was supported by grant number U54CA096297 and grant number 1U54CA163071-01A1. Furthermore, we want to thank the support of the Puerto Rico Clinical and Translational Research Consortium (8U54MD007587-03).

Compliance with Ethical Standards

Conflict of interest No conflicts of interest disclosures from the authors and state compliance with all ethical standards.

Human Studies and Informed Consent This article does not contain any studies with human participants performed by any of the authors.

Animal Studies This article does not contain any animal studies by any of the authors.

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