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Genetic Services to the Latino Population in the United States

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Abstract
In 1998 Latinos (Hispanics) in the United States number 30 million persons and account for 11.3% of the total population, while it is predicted that by the year 2020 they will become the largest minority. This article describes the demographics and health profile of the Latino population in the United States. A brief account is given of common cultural traditions and health beliefs that modulate the interaction of this population with the health delivery system in general, and that of genetic services in particular. Further, some problems in the access to, and utilization of genetic services are outlined, and the experience of a project designed to overcome those problems in New York City is described.

Introduction: Who Are the Latinos?

While the terms Latino and Hispanic are synonymous, the latter errs by excluding Brazilians, and by resonating more with the European culture of Spain (which has little to do with today's Latinos) rather than with the preexistent indigenous cultures in the subcontinent and the important African American cultures. Moreover, the term Hispanic emphasizes the Spanish language as a common feature, while neither Brazilians nor some US-born Latinos speak it. Thus, most organized community groups in the US prefer the term Latino because it resonates better with the self-identification with a Latin American heritage. The US Bureau of the Census, from which most demographic data are derived, uses the term Hispanic, defined as 'persons of Mexican, Puerto Rican, Cuban, Central or South American or other Spanish culture or origin, regardless of race' [1]. The fact that Latinos can be of any race reflects the wide variety of gene pools that have contributed to current Latin American populations: several hundred different American Indian groups or tribes; South, Central and Eastern Europeans; Africans from different geographical origins; peoples from the Middle East, South and East Asia, and others. Throughout centuries these populations have gone through a significant process of admixture, leading to the large genetic and phenotypic variation currently characteristic of Latin American populations.

Latinos in the United States are the peoples with cultural, ethnic and/or geographical roots in the Latin American subcontinent and the Spanish-speaking Caribbean. Rigid classifications on the basis of race, physical appear-

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ance, surname or language fail to capture the highly heterogeneous nature of these populations. Indeed, the demographic structure of Latinos is varied and complex [2] and includes immigrants from different countries, variable ethnicities and distinctive regional settlement patterns as well as generations of US born [3]. Moreover, consecutive immigration waves and the process of social acculturation have added significant cultural variations within and among different Latino subgroups.

Demographics of Latinos

According to 1998 estimates of the US Bureau of the Census, the distribution of the classified population groups is as follows: Whites, non-Hispanic (72.2%), Blacks (12.1%), Hispanics (11.3%), Asian/Pacific Islanders (3.6%) and American Indians (0.7%) [4]. The 30 million Latinos are experiencing a rapid population growth. Between 1980 and 1990 there was a 53% increase, one of the highest in the country (eight times higher than the white non-Hispanic population) [5], due both to immigration and high fertility. It is predicted that by the year 2020 Latinos will be the largest minority group in the United States, and by 2050 Latinos and African-Americans alone will constitute over one third of the total US population, while the Whites, non-Hispanic, will fall below 50% [6]. The median age of Latinos (26.5) is significantly lower than the median for all the population (35.3) and the lowest of any other ethnic group [4]. About 71% of Latinos are US born, while 29% are immigrants, and about two-thirds speak Spanish at home [7].

The US Bureau of the Census classifies Hispanics into five main subgroups according to national/geographic origin: Mexican, Puerto Rican, Cuban, Central/South American and Other. The largest subgroup is the Mexican origin (64%), followed by Puerto Ricans (11%) and Cubans (5%). The geographical distribution of these groups reflects historical immigration and settlement patterns, with Mexicans predominating in the Southwest, Puerto Ricans in the Northeast and Cubans in Florida. Ninety percent of Latinos live in urban areas and their landscape is evolving dramatically since the 1980s, with large numbers of immigrants from Mexico, Central America and the Dominican Republic settling in the major urban centers, predominantly Miami, New York, Los Angeles, Washington and Chicago.

While the Census classification is not discriminative enough to disaggregate important geographic and cultural subgroups, it does reveal some sociodemographic differences. The socioeconomic and education levels of Latinos are the lowest of the US population, albeit with significant differences among subgroups. In 1990, 33% of Puerto Ricans lived below the poverty level, compared with 28.4% of Mexican Americans, 18.5% of Central/South Americans, 15.2% of Cubans and 11.6% of Whites, non-Hispanic [8]. The proportion of high school graduates was 79.6% for White, non-Hispanic, 70% for Cubans, 58.5% for Central/South Americans, 55.0% for Puerto Ricans and 44.1% for Mexican Americans. The proportion of female-headed households and the family size are higher than among non-Hispanics. Unemployment among Latinos is generally 40–60% higher than among White, non-Hispanic, and employment is concentrated in lower status occupations such as service workers [9].

In summary, the Latino population in the USA is constituted by heterogeneous ethnic, cultural and geographic subgroups, which in the aggregate are characterized by high fertility and rapid population growth, lower median age, lower income, lower education level, and high rate of unemployment or low-skilled jobs.

Health Profile

The assessment of the health profile of Latinos is hampered by severe limitations of existing data, due to a number of shortcomings of the national health data systems [9, 10]. General age-adjusted mortality rates in Latinos are highest in Puerto Ricans, but still they are lower than in White, non-Hispanic [11]. The disease-specific death rates show some peculiarities, and although they vary somewhat within Latino subgroups, they are much lower than for Whites non-Hispanic for diseases of the heart and cancer [12]. On the other hand, they are higher for homicide, HIV infection and perinatal causes. Infant mortality is highest among Puerto Ricans (10.2 per thousand), compared with Mexican Americans (7.7), Cubans (7.6) and Whites (7.4) [13].

Regarding morbidity, a most referred source of data is the 1982–1984 Hispanic Health and Nutrition Examination Survey [14, 15], conducted on the three largest subgroups of Latinos living in the continental United States: Mexicans, Puerto Ricans and Cubans. This and other studies show higher prevalence rates of asthma [16], non-insulin-dependent diabetes [17], obesity [18], hypertension [19, 20], immunizable infections, tuberculosis, sexual and sexually transmitted diseases [21], AIDS [22] and depression, particularly in Puerto Ricans [23]. On the other hand, Latinos have similar or lower rates than Whites

for cardiovascular diseases [24] and lower overall rates of cancer. However, some types of cancer have higher rates in some Latino subgroups, such as cancer of the stomach, cervix and liver [25, 26].

The overall prevalence of genetic diseases and birth defects in Latinos is not typically different from other population groups. However, congenital malformations registries have shown higher rates of neural tube defects and Down syndrome among Latinos [27]. The overall frequency of Mendelian conditions is similar to other population groups, but Latinos have relatively high frequencies of sickle cell disease and thalassemias, due to African and Mediterranean admixtures [28, 29]. Some autosomal recessive conditions have higher frequencies because of founder effects and/or inbreeding in the original populations, like spondylocostal dysplasia [30] and Hermansky-Pudlak syndrome [31] in Puerto Ricans. On the other hand, cystic fibrosis (CF) is characteristically less frequent than among Whites, non-Hispanic [32].

Access to Health Care

It has been consistently reported that Latinos are least likely to be linked to a regular source of health care and to visit a doctor during an illness [33, 34]. When they do, they tend to visit public health care facilities, hospital outpatient clinics or hospital emergency rooms [35]. Moreover, Latinos are more likely than other ethnic groups to use nonprescribed over-the-counter and homemade medicines [36]. In addition, due to poverty and/or unemployment, they are usually unable to afford medical care, and 25–44% lack health insurance [37, 38]. This is a particularly serious problem for Latino children and adolescents, 28% of whom lack health insurance, compared with 16% of African Americans and 11% of Whites [39]. These factors are compounded with a number of inconveniences that Latinos usually confront in their interactions with the health care system. The following were among the barriers cited by Latinos in different nationwide community surveys: unfriendly design and organization of the services delivery; service hours that do not take into account the life realities of the Latino community; lack of transportation or baby-sitting arrangements; language, class and cultural differences; lack of Spanish speaking personnel; prejudice and social discrimination [40, 41].

Common Traditions and Health Beliefs

In spite of different existing subcultures and an extensive heterogeneity, Latino subgroups share some core common traditions and health beliefs. Prominent among these is the important role of the extended family in everyday life and particularly in reproductive decisions. For instance, the participation of close family members and the extended families in decision making is not unusual given the collective nature of Latino culture [42]. Immediate and extended family members often participate in decision-making for some Latino families [43]. *Familismo* emphasizes the notion of interdependence over independence, affiliation over individualism and cooperation over confrontation. The cultural concept of *familismo* translates into an upholding of family loyalties that extend beyond that of the nuclear family.

Latinos put strong value in interpersonal trust through warm and friendly relations *(personalismo, confianza)*, while at the same time adhering to strict lines of authority and respect for others *(respeto)*, particularly the elder [44]. Folk health beliefs are the base for explanations of some symptoms, such as *mal de ojo* (evil eye) and *empacho* (upset stomach). In addition, the actual expression of symptoms and signs is influenced by folk health beliefs, as is the case of *ataque de nervios* (nerve attack) and *susto* (fright) [45]. The fact that these phenomena have a strong sociocultural construct make them no less real, and may significantly affect the physician/patient relationship. Health beliefs may include supernatural explanations for the occurrence of birth defects and may surface in the context of genetic counseling [46, 47].

Provision of Genetic Services to Latinos

In view of the realities described above it is clear that the provision of comprehensive genetic services to Latinos, particularly genetic counseling and prenatal diagnosis, faces significant challenges [47, 48]. Concerns that should be high in the agenda of genetic professionals are the realization of the marginal socioeconomic and educational position of many Latinos and the frequency of single motherhood and its impact on reproductive decision-making. Among many distinct issues, special attention must be given to possible conflicts between provider and patient resulting from cultural insensitivity of the former. Examples would be a disregard for the patient's preventive health practices, or for the particular meaning that disability may have in the family and how this may

influence the patient, or for the patient's attachment to tradition or religion. While it is true that Latinos share many cultural similarities, heterogeneity is a most remarkable characteristic; stereotyping, therefore, is always unwarranted, commonly leading to discriminatory practices. A special challenge is to avoid the temptation of paternalism in face of social and educational gap between the provider and the patient [47].

The role of the extended family in the patient's reproductive decisions may render the Western models of 'patient autonomy' and 'nondirective' genetic counseling unrealistic in many situations [42, 49]. Submissive attitudes of the woman with respect to the husband/partner are common and must be recognized and managed sensitively by the provider. The extreme shortage of Latino genetic professionals imposes a severe task on service providers to be culturally competent and sensitive when dealing with Latino patients in the context of genetic services.

The above-mentioned principles are being applied by the Division of Medical Genetics of Beth Israel Medical Center, which since 1986 has been providing culturally and linguistically appropriate comprehensive genetic services to the significant numbers of Latino patients in its catchment area in South Manhattan. The patient population served is very diverse in terms of its racial, ethnic, socioeconomic and religious composition. Forty-five percent of the patients served are Whites, non-Hispanic, 30% Latinos, 13% Blacks, non-Hispanic and 12% Asian. Genetic services are provided by a clinical geneticist and a genetic counselor, who are both bilingual bicultural Latinos, and include genetic counseling, prenatal and postnatal genetic diagnosis and management of a variety of birth defects and hereditary disorders. We describe below the main characteristics of the Latino population served and some challenges confronted with real patient encounters.

In the past 10 years, over 3,600 Latino patients have received prenatal genetic counseling services in our center. Forty percent of these patients were born outside of the United States and 80% were either monolingual Spanish speakers or bilingual. Forty-eight percent of Latino patients had not completed high school. As to occupational status, 40% were unskilled workers, 29% were in professional jobs, 27% were unemployed and 4% were students. All patients had some health insurance, and 23% were the recipients of Medicaid, the government insurance for the poor. The proportion of Latino subgroups were as follows:61% Puerto Rican, 21% Dominican, 13% Central and South American, 3% Cuban, and 2% Mexican.

The most common indication for referral for prenatal genetic services was advanced maternal age (66%). Abnormal maternal serum screening was the next most common referral indication (24%). Family history of genetic diseases (5%), abnormal prenatal ultrasound (2%), multiple pregnancy losses (1%) and parental concern (2%), comprised the remaining reasons for referral. Most patients (44%) were between 14 and 17 weeks of gestation at the time of consultation, while 36% were between 18 and 23 weeks gestation. A sizable minority (one third) of the patients did not know why they were referred for genetic counseling. When questioned as to what they would do in the event of an abnormal finding in amniocentesis, 58% stated that they would terminate the pregnancy, 6% expressed that they would continue the affected pregnancy and 36% were unsure.

In order to look into cultural traditions and health beliefs regarding prenatal genetic diagnosis, we recently administered a questionnaire to 100 Latino patients prior to genetic counseling. The following areas were assessed: attitudes toward prenatal testing, sex selection and abortion, perception of genetic risk and risk of amniocentesis, level of anxiety with respect to amniocentesis and knowledge of prenatal diagnosis and amniocentesis. The following are highlights of the responses:

- Two thirds correctly identified that amniocentesis detects chromosomal abnormalities, but a similar proportion also believed incorrectly that it could detect as well all genetic diseases and mental retardation, or that it could predict the overall health of the future child. Fifty three percent incorrectly believed that a normal result assured that the child would be normal in all respects. Only 35% knew that amniocentesis could also diagnose spina bifida and 49% knew that it could determine fetal sex.
- The most common reasons that would make patients decide to have amniocentesis were the following; 31% because of influence from their obstetrician, 31% for reassurance from a normal result, and 25% to have the option to interrupt an abnormal pregnancy.
- The most common reasons that would deter from having an amniocentesis were fear of miscarriage (63%) and fear of pain (11%). However, most patients (83%) could not identify the possible complications of amniocentesis.
- Thirty percent stated that the abortion of an abnormal fetus would not be an option because of religious and/or moral beliefs. None of the patients surveyed would abort a pregnancy on the basis of fetal sex.

- About one third of the patients reported high levels of anxiety regarding the pain of the procedure and the chance of an abnormal result. Those who had perceptions of higher risk of having a child with a genetic abnormality reported higher levels of anxiety. Almost half the subjects reported being very anxious about the risk of harm to the pregnancy by the procedure, and about the accuracy of the results.

Our data indicate that only approximately two-thirds of Latino patients with medical indications for amniocentesis actually decide to undergo the procedure after genetic counseling, as compared with over 90% of Whites non-Hispanic.

Case Stories

The following patient examples selected from our experience demonstrate the cultural diversity, life stories and range of issues present in Latino patients receiving genetic counseling and diagnostic services.

Mrs. G is a 39-year-old woman of Puerto Rican descent. She and her 5 children have been residing in the United States for the past 5 years. They live with Mrs. G's sister and her family. Mrs. G was married in Puerto Rico but separated from her husband after learning that he was involved with another woman. Mrs. G's husband recently came for a visit to New York and they renewed their relationship. As a result, Mrs. G is currently pregnant, while her husband returned to Puerto Rico. Although this was an unplanned pregnancy, religious reasons preclude Mrs. G to consider an abortion. Her sister, however, favors an interruption because of the lack of support coming from Mrs. G's husband and her precarious financial situation. Mrs. G was referred for genetic counseling because of advanced maternal age. She had an amniocentesis as she felt pressured by her obstetrician to do so, and the fetal chromosome analysis was trisomy 18. Mrs. G believes that her husband's mistress has given the pregnancy a *daño* and plans to see a *curandero* to try to resolve the situation.

As this case shows, religion plays a large role in the lives of many Latinos. While a significant number of Latinos are Catholic, African and indigenous supernatural beliefs strongly influence the practice of religion among Latinos [50]. Among other religions practiced by Latinos are Protestantism, Baptism and Judaism. Because of Catholic influence, prenatal diagnosis is viewed skeptically by some Latinos because of its association with abortion [50]. Independently of their stated religious affiliation, some Latinos believe that individuals can bring on disease through witchcraft or *brujeria*. Such practices are believed to cause all types of congenital anomalies. *Daño* is the belief that someone has brought a curse upon an individual by engaging the services of a witch. The curse can be eradicated by the aid of a *curandero* or indigenous healer [51]. The knowledge of Latino indigenous beliefs enables health professionals to show empathy and better understand the choices that patients may make in prenatal genetic services.

Mr. and Mrs. R are from the Dominican Republic. They have been living in the United States for over 2 years. They travel frequently to Santo Domingo to visit relatives. Mrs. R is a homemaker and has had 4 children. Mr. R is self-employed and owns a *bodega* in their neighborhood. Mrs. R is 29 years old and Mr. R is 35. Mrs. R was referred for genetic counseling by her obstetrician because of an abnormal maternal serum biochemical screening result which increased her risk of having a child with Down syndrome. The couple came together to the genetic counseling session and appeared anxious and frustrated. They reported having been told by their obstetrician that 'the baby is probably abnormal' and that they had to speak to a genetic counselor about it. Mrs. R feels at fault since she has not been eating well with this pregnancy. Mr. R dominates the session leaving little room for Mrs. R to say much. When the genetic counselor offered an amniocentesis, Mr. R replied that he did not want his wife to have the test. He contended that in his country women have babies all the time and there is never any problem. All of his children were born fine in the Dominican Republic. Mr. R believes that 'the more you test, the more you will find'. The couple leaves the session.

This case illustrates the patriarchal nature of some Latino families. It is not unusual for men to make decisions while women are more instrumental in the caring of children and running of the household [52]. This deferring to men seen among some Latinas, challenges health professionals to find ways to work with their partners, especially around issues of health education and prevention.

N is a 15-year-old Latina and she is 22 weeks pregnant. Her boyfriend, R, is 16 years old. Both were born in the United States from Mexican parents. They are both high school students and were referred for genetic counseling because of a severe congenital heart defect in the fetus diagnosed by ultrasound and echocardiography. At this time, N and R are not in good terms with each other, and N comes to counseling alone. R accused N to be too possessive, and has started dating another girlfriend who 'does not expect him to be with her all the time'. N does not want to have a child who will require substantial needs and complicated course and who may not survive for long. However, she is convinced that having this child would be the only way to keep a tie to R.

It is apparent that for many Latinos, having children is considered an essential function of the family [50]. Thus, the loss of a child or a pregnancy signifies a loss of expectations and hope for the future. In this case, the future child is seen as an instrument to recover the relationship with the boyfriend, and that goal seems to override the

fear of the predicted disability. A study on attitudes on children with disabilities showed that Latino fathers were more likely than African American and Caucasian fathers to deny the disability in their children [53]. In providing genetic counseling to Latino patients, it is critical to understand not only the influence of culture on the ability to manage a particular situation or express grief, but also the motivation behind which choices are made.

M is a 40-year-old woman of Cuban ancestry and H is a 42-year-old man of Uruguayan descent. Both were previously married but had no children. M and H have undergone extensive infertility treatment for the past 5 years. After multiple attempts with in vitro fertilization, they achieved a pregnancy. Both M and H come from large families and each has many nieces and nephews. Additionally, both families have pressured them to have children since they married at 'a very late age'. M had had a previous abortion with her first husband at age 20 and had not been able to conceive since. H always attributed the infertility to M, although there was no medical reason for this belief. M's obstetrician referred the couple for genetic counseling because of advanced maternal age. M is a devout Catholic and would not terminate this pregnancy for any reason. She feels tremendous guilt over her previous abortion and blamed her ex-husband for having induced her to it. M seems to identify her womanhood with being a mother and until she is one, she will not feel complete as a woman. H has made it clear that although he very much wants to have a child, he would not keep the pregnancy if a chromosome abnormality is found.

As demonstrated in this case, patients who adhere to the basic tenets of Catholicism, may view prenatal diagnosis as unnecessary, especially if abortion is not a perceived option [50]. Many Catholic Latinos hold the belief that illness or disability is God's will and persons should not interfere. Another prevailing belief among Catholic Latinos may be that illness or congenital anomalies occur because of God's disapproval with the previous behavior of the person [54]. When working with Latino patients who hold such beliefs, it is important to explore the significance given to these cultural notions as they influence decisions that patients make. Furthermore, health professionals also need to recognize that in some couples, partners may hold divergent views about the same condition. Additionally, it is not uncommon that definitions of disability vary among Latino groups [50].

Discussion

The available demographic and health statistics on USA Latinos reviewed above indicate that this is a heterogeneous, sizable and vulnerable ethnocultural minority, characterized by socioeconomic and educational marginalization. Intergenerational poverty is increasing its impact on health status and utilization of health services, including genetic services. While Latinos share many characteristics, values and traditions, important differences exist between subgroups, influenced by educational level, socioeconomic status, migration history, age, duration in the US, acculturation and assimilation, rural versus urban residency, country of origin, personal history and political experiences [55].

The fact that health status of Latinos in the US is not worse than it is is probably due to the strengths of the Latino community, including the existence of supportive networks of family and friends, which help in their adaptation to life under the dominant US culture [56]. However, acculturation to mainstream US values and norms is a double-edged sword. On the one hand it offers expectations of improved social and economic status. On the other hand, it has the cost of losing cultural values and resources, which in turn, puts individuals at risk [57]. Actually, studies indicate that some forms of cultural assimilation are harmful to the health of Latinos and lead to increased infant mortality, low birth weight, overall cancer rates, high blood pressure and adolescent pregnancy [9].

Be it as it may, there is no doubt that the access to health care of Latinos is significantly hampered by social, economic and cultural barriers. This reality affects genetic services as well, which by nature require a higher level of education and comprehension on the part of patients, and cultural awareness by genetic professionals. Cultural attitudes and behaviors can impact on the process of genetic counseling, which is often operating in a realm that may be in contrast to dominant Latino culture. Indeed, the paradigm of genetic counseling is based on such Western values as direct information-giving, individual decision-making and a future time orientation [49] that may not apply verbatim to prevailing Latino culture. Culture influences personal characteristics, family structure and function, the manner in which decisions are made and the choices that are elected regarding healthcare, illness and disease [58]. The findings from the survey described above indicate the importance of recognizing the clinical and psychological needs of patients as well as the impact that culture has on individual's attitudes, behaviors and decision-making.

The Beth Israel Medical Center's program has been successful in eliminating economic barriers through a very flexible zero-based sliding fee schedule based on income. Furthermore, the provision of services by bilingual-bicultural genetic professionals, who speak Spanish

fluently and also resonate with Latino culture, have gone a long way in minimizing cultural and language barriers to genetic services. Even so, a disproportionate number of Latino patients at increased genetic risk remained unimpressed by the actual risk figures or by what prenatal diagnosis has to offer them today. This may be a consequence of the interplay of several factors, such as life experiences associated with much higher risks for more severe problems (like social marginalization, destitution, drug addiction or HIV infection), a culture system that privileges optimism in outcomes or relies in religious beliefs for comfort, and lack of education and sophistication to grasp the complexities of available reproductive options made available by current technology.

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