

**LATINOS' HEALTH CARE ACCESS IN SOUTHWESTERN  
PENNSYLVANIA**

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## **LATINO'S HEALTH CARE ACCESS IN SOUTHWESTERN PENNSYLVANIA**

Patricia Isabel Documét  
University of Pittsburgh, 2001

Latinos are the ethnic group with the worst health care access in the United States. Most studies focus on the financial determinants of access; culture and language have been studied less. Health care access data on Latinos in southwestern Pennsylvania (SWPA) are virtually non-existent. This study aimed at 1) investigating the relationship of income, culture and language to health care access and 2) understanding the cultural and language barriers to health care in this population

Participant observation served to construct a sampling frame of SWPA Latinos, to describe their community comprehensively, and to explore language and cultural barriers to health care they experience. Two hundred six Latinos were surveyed; analysis included estimate construction and logistic regression.

SWPA Latinos belong to several overlapping communities, connected by traditions and their concept of family. They build social networks to exchange information and support, and reproduce an extended family model.

Socioeconomic differences and geographic distance divide them.

Health care access for SWPA Latinos is not equitable, because characteristics of the social structure affect it. Income determines insurance status, insurance status determines having a regular source of care, having a

regular source of care determines utilization of services. Even native Spanish speakers with high English proficiency have difficulties communicating about health issues in English. Latinos prefer warm, committed providers who relate to them personally. Discrimination decreases service utilization and effectiveness.

Many SWPA Latinos use informal arrangements to obtain care through community networks, thus circumventing the formal health care delivery system. Those without insurance use these arrangements out of need. Those with insurance use them to have family involvement in health issues. Informal arrangements are creative, affordable, and culturally acceptable. However, they pose risks for patients' health. Therefore, they cannot replace equitable access to health care within the formal system.

A scattered population and loose community organization make resources more scarce and difficult to find. Latinos have not yet organized to request better health care options, partly because their community is not cohesive. Latinos' Health care may improve if cultural competency training is given to providers in SWPA and translators are provided to non-English speaking patients.

# **ACCESO A LOS SERVICIOS DE SALUD DE LOS LATINOS EN EL SUROESTE DE PENNSYLVANIA**

Patricia Isabel Documét  
University of Pittsburgh, 2001

Los latinos constituyen el grupo étnico en los Estados Unidos con los peores indicadores de acceso a los servicios de salud. La mayoría de los estudios se centran en los determinantes económicos de acceso; la cultura y el idioma han sido poco estudiados. Casi no existen datos sobre el acceso a los servicios de salud de los latinos en el suroeste de Pennsylvania (SPA). Los objetivos de este estudio son: 1) investigar la relación entre ingreso, cultura e idioma con acceso a servicios de salud y 2) entender las barreras culturales e idiomáticas que enfrenta esta población.

Se usó observación participante para construir un marco muestral, obtener una descripción amplia de la población y explorar las barreras culturales e idiomáticas desde el punto de vista de la población estudiada. Se efectuó una encuesta a 206 Latinos. El análisis estadístico de los datos incluyó construcción de estimados y regresión logística.

Se encontró que los Latinos en el SPA constituyen varias comunidades que se superponen; están conectados por sus tradiciones y su concepto de familia. Construyen redes de comunicación social para intercambiar

información, compartir apoyo y reproducir el modelo de la familia extendida. Las diferencias socioeconómicas y la distancia geográfica los separa.

El acceso a los servicios de salud de los latinos en el SPA no es equitativo, ya que es afectado por características de la estructura social. El ingreso determina tener seguro; el tener seguro determina tener una fuente usual de cuidado de la salud. Es difícil comunicarse en inglés acerca de salud para aquellos para quienes el castellano es su lengua materna, incluso si hablan bien el inglés. Los latinos prefieren personal de salud que sea cálido y comprometido con dar servicio, con quienes se pueden relacionar de una manera personal. La discriminación ocasiona que los servicios de salud sean menos usados y cuando se usan, que sean menos efectivos.

Muchos latinos en el SPA usan arreglos informales para obtener cuidado de salud a través de su red social, sin recurrir al sistema formal de salud. Aquellos que no tienen seguro usan estos arreglos por necesidad. Aquellos que tienen seguro los usan para obtener cuidado personalizado e involucrar a la familia en asuntos de salud. Los arreglos informales son creativos, de bajo costo y culturalmente aceptados. Sin embargo, pueden poner la salud del paciente en riesgo. Por lo tanto, no pueden reemplazar el acceso equitativo al sistema formal de salud.

Una población dispersa y una organización comunal incipiente hacen que los recursos sean escasos y más difíciles de obtener. Los latinos en el SPA aún no se han organizado para reclamar mejores opciones para el cuidado de su salud, en parte porque la comunidad no está unida. El cuidado de salud de los latinos puede mejorar si se capacita al personal de salud en “competencia cultural” y si se provee traductores para los pacientes que no hablan inglés.

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## **I. Introduction and objectives**

### ***A. Introduction***

Over the years, people in the public health arena have talked about the relationship between socioeconomic status and health. We only need to look at published public health literature to realize the persistence of these themes. Several of the causes of disease among the poor have been addressed for a good portion of the population of the world. For example, in the U.S., most people have access to proper sanitation. If this is the case, we may ask with Link and Phelan (1996): why does the relationship between lower socioeconomic status and ill health persist even in so-called developed countries? They argue that, at any time in history, resources such as knowledge, money, power, prestige, and social connections increase people's ability to avoid disease, and to cope with its consequences. To truly decrease inequalities in health status, we need to focus on the social inequalities of our times. Today, the lack of proper access to health care, as the lack of access to running water did before, reflects an unequal distribution of resources that should be addressed.

Policy developers and program managers in the U.S. have been preoccupied with the issue of health care access for decades. Traditionally, ethnic minorities and the poor have had the most difficulties in obtaining quality health care (Aday et al, 1998; Aday et al, 1984, Weissman & Epstein, 1994; Zambrana, 1996 a). Latinos represented 13% of the U.S. population in 2000, constituting the fastest growing minority group in the country (Grieco & Cassidy, 2001). They are at a disadvantage when it comes to access to health care, when compared to other groups in the U.S, as shown by various health

care access indicators. Latinos are the group with the largest proportion of uninsured people, the largest proportion of uninsured children, the smallest proportion of workers that receive health insurance as a job benefit, the largest proportion of people who have not had contact with the health system in the past year, and the largest proportion of consumers who say they experience barriers when they try to obtain health care (Gray & Puente, 1996; Hajat et al, 2000). These disparities point to a non-equitable distribution of health care resources among the population of the U.S. Social justice is a paradigm concerned with those actions that bring about the most good for society as a whole. From a social justice point of view, equity would exist if access to health care were determined by need, rather than by social and economic factors (Aday et al, 1998).

Most studies on access to health care focus on financial barriers to health care access. However, there are data that suggest that cultural and language barriers are also important in determining Hispanics' inability to obtain health insurance, identify a source of care, and receive actual services. To date, the role of cultural attitudes in determining health care access has not been thoroughly studied (Zambrana, 1996 a). Weinick and Krauss (2000) suggest that more detailed study of the societal and health system factors responsible for health care access disparities for Latinos may help identify potential areas of intervention.

Southwestern Pennsylvania (SWPA), defined here as the seven county region including Allegheny, Beaver, Butler, Fayette, Greene, Washington, and Westmoreland, has traditionally had a small Hispanic population. There are indications that the number of Hispanics in SWPA is rapidly increasing. Preliminary results of Census 2000 indicate that there are now 17,500 Latinos in SWPA, a 44% increase since 1990 (U.S. Census Bureau, 2001). Information, other than summary demographic data on the Latino population in the area, is very scarce. I could obtain two written accounts dealing with Latinos in this area, and none of them has been published. Patrick's (1973) monograph, apparently a term paper, has the main goal of describing the spatial distribution of Latinos in the Pittsburgh metropolitan area. Patrick reviewed 1970 U.S. Census materials and interviewed some members of the Latino

community, a few of whom are still in the area today. At that time, the number of Latinos was small, they were for the most part not aware of the existence of each other, and they were essentially not organized. Wilson's (1998) term paper was written for a history class, at Carnegie Mellon University. She interviewed a limited number of Latinos in the area, and the paper describes a portion of the Hispanic community and some of its history, dating to a few decades. I could not find more comprehensive descriptions of this population group.

Data on health care access for Latinos in SWPA are virtually non-existent. The only paper I could find is a monograph by Holly (1997), presenting 1990 census data on the number of linguistically isolated people in Allegheny County and describing her experiences trying to assist Spanish monolingual Latinos in their contacts with the health system. The Latino population in SWPA encounters a health system that, unlike those on the East and West Coasts, does not offer specific services for them. Therefore, Hispanics in this region are likely to be exposed to cultural and language health care access barriers, in an unmodified way. This provides an opportunity to study them fully at a time when the demographic profile of this population group is changing.

The present study addresses the issues of financial, cultural and language barriers to health care in (SWPA). Survey research and participant observation were used, due to the nature of the determinants of access studied, and to the importance of gaining a perspective of the issue from the point of view of Latinos themselves. The use of a combination of quantitative and qualitative techniques has been considered appropriate for research on health care access by Aday et al (1998), and specifically for research with Hispanic populations by Becerra and Zambrana (1985) and by Freidenberg et al (1993).

According to Aday et al (1998) health services research produces knowledge about the performance of the health care system. Policy analysis applies that knowledge to evaluate policy alternatives and to define problems and priorities. It is anticipated that an improved understanding of the extent and characteristics of the barriers to health care access in this community, and of the resources the community uses to obtain health care, can serve several purposes. First, at the local level it can serve policy developers and service

delivery organizations to provide more appropriate services to the community in SWPA. It can also be a resource to the Latino community in SWPA to request certain services. Therefore, special efforts will be made to disseminate the results of this research among:

1. Providers of health services in the area, including the Pennsylvania Health Department, the Allegheny County Health Department, and public and private institutions, and
2. Local groups and organizations of the Hispanic community in SWPA.

Second, at the national level, an enhanced understanding of how barriers to health care access operate, and what resources Latinos tend to use and value, can serve policy makers and health providers to understand the needs of their population. This understanding might be the starting point for developing improved services in an equitable manner. Finally, new questions and hypotheses about health care access may emerge from the results of this study. Some of these may be worth pursuing in the future.

### ***B. Goals of the study***

1. To investigate the relationship of financial, cultural and language factors to potential and realized access to health care for Hispanics in southwestern Pennsylvania (SWPA), the region which includes Allegheny, Beaver, Butler, Fayette, Greene, Washington, and Westmoreland counties.
2. To understand the characteristics of cultural and language barriers to health care for Hispanics in SWPA.

### ***C. Specific objectives***

#### 1. Adults

- a. To determine whether cultural, language and/or financial factors affect potential access to health care for Hispanics in SWPA, as measured by having health insurance and having a regular source of health care.

- b. To determine whether cultural, language and/or financial factors affect realized access to health care for Hispanics in SWPA, as measured by having a visit to the doctor in the past year, having a visit to the dentist in the past year, having a blood pressure determination in the past year, and being generally satisfied with received health care.

## 2. Children

- a. To describe the characteristics of potential health care access for children 2 to 5 years of age, as measured by having health insurance and having a regular source of health care.
- b. To describe the characteristics of realized health care access for children 2 to 5 years of age, as measured by having a visit to the doctor in the past year, having required immunizations and being generally satisfied with received health care.

## 3. All ages

- a. To describe in-depth the characteristics of language and cultural barriers to potential and realized access to health care, as perceived by Hispanics in SWPA.

## ***D. Hypotheses***

### 1. Adults

#### *a. Potential Access*

- Hispanic adults in SWPA with annual family incomes under \$20,000 are less likely to have health insurance and a regular source of care than those with higher incomes.
- Hispanic adults in SWPA that have lower English proficiency are less likely to have health insurance and a regular source of care than those with higher English proficiency.
- Hispanic adults in SWPA that are less acculturated in the U.S. are less likely to have health insurance and a regular source of care than those that are more acculturated.

- Hispanic adults in SWPA that use the services of “traditional” healers are less likely to have health insurance and a regular source of care than those who do not use such services.
- Language and cultural factors pose obstacles for SWPA Latinos to obtain health insurance and a regular source of care.

*b. Realized Access*

- Hispanic adults in SWPA with annual family incomes under \$20,000 are less likely to have seen a doctor or a dentist in the past year, to have a blood pressure determination in the past year and to be satisfied with the care they received than those with higher incomes.
- Hispanic adults in SWPA that have lower English proficiency are less likely to have seen a doctor or a dentist in the past year, to have had a blood pressure determination in the past year and to be satisfied with the care they received than those with higher English proficiency.
- Hispanic adults in SWPA that are less acculturated in the U.S. are less likely to have seen a doctor or a dentist in the past year, to have had a blood pressure determination in the past year and to be satisfied with the care they received than those that are more acculturated.
- Hispanic adults in SWPA that use the services of “traditional” healers are less likely to have seen a doctor or a dentist in the past year, to have had a blood pressure determination in the past year and to be satisfied with the care they received than those who do not use such services.
- Language and cultural factors pose obstacles for SWPA Latinos to obtain preventive and curative medical and dental care.

## **II. Conceptual framework**

### ***A. Introduction***

Before embarking in a study of health care access for Latinos in southwestern Pennsylvania (SWPA), it is necessary to define and explore several concepts. In this chapter, I will first define the concept of health care access and describe a framework for its study. If our intention is to measure access, we need to explore the various indicators that have been used to measure its dimensions. A discussion of the determinants of access ends the discussion on access to care. These determinants may relate to the social structure or to health needs, and this distinction is important to put the issue of access into a social justice perspective.

The second concept that needs exploration is that of “Latinos.” Who are they? Do they constitute a clearly defined group or not? A discussion of these topics follows a demographic and cultural profile of Hispanics in the U.S.

The third point of importance is to explore what is known about the health status and health care access of Latinos in the United States, as well as the determinants of access for this population.

The fourth and last concept to be explored is the population to be studied, that of Latinos in SWPA. For the purpose of this research, SWPA has been defined geographically and includes the counties of Allegheny, Beaver, Butler, Fayette, Greene, Washington, and Westmoreland. A demographic profile of the Latino population in SWPA is presented, as are some data although scarce on their health status and health care access.

## ***B. Access to health care***

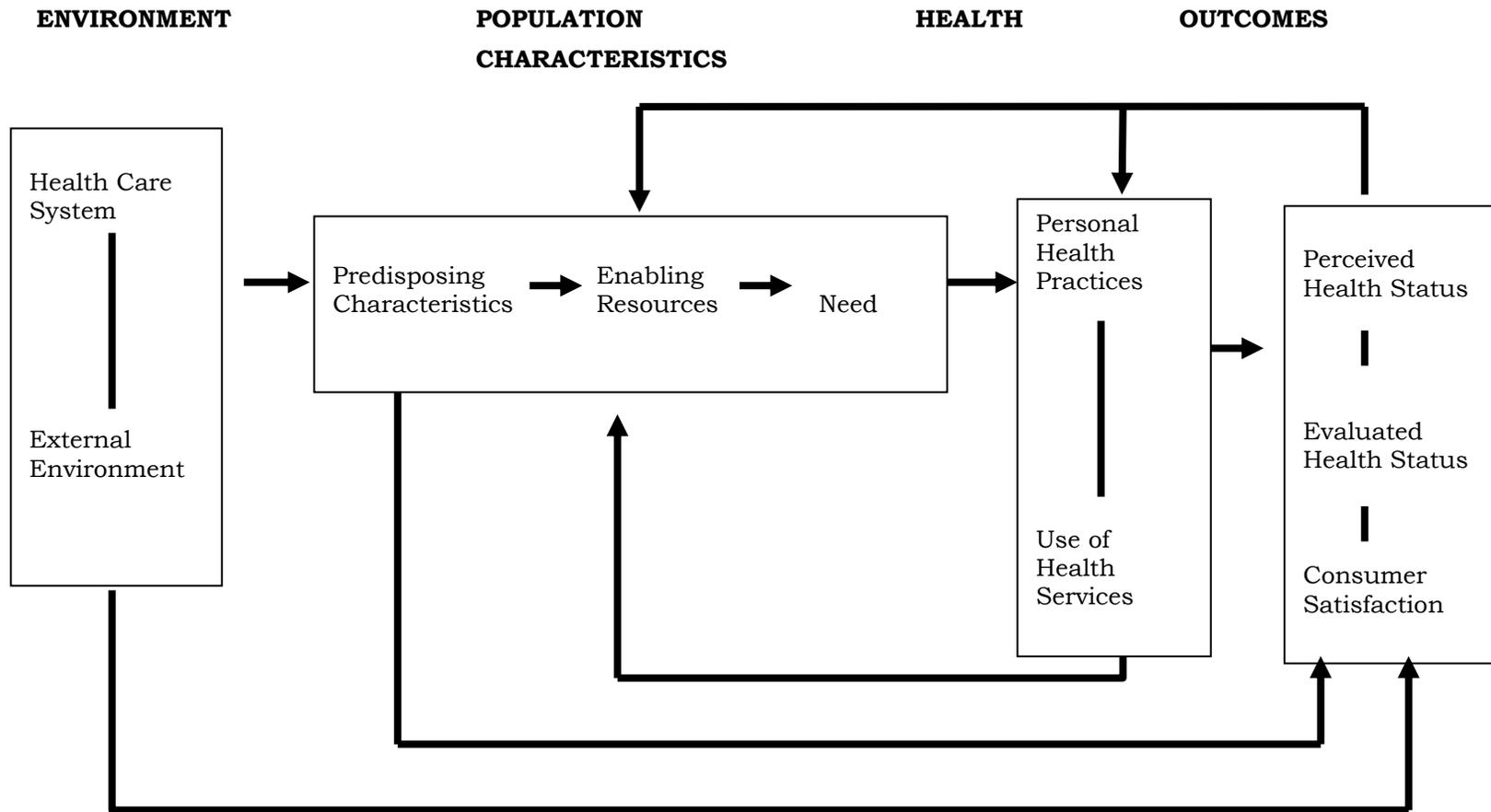
### 1. Model for the study of health care access

Access to health care has been defined in a variety of ways. It may mean availability of health services or use of health services. From the point of view of use of services, access can be conceptualized as “those dimensions which describe the potential and actual entry of a given population group to the health care delivery system” (Aday, 1984, p. 13). In the 1960s, Andersen (1995) devised a framework for the study of health care access, focusing on health care service utilization as the endpoint. According to this framework, demographics, social structure characteristics, and health beliefs are predisposing factors for the use of health services. Enabling resources are personal, family and community characteristics. Need is included as a determinant of health care use. The main criticism of this model was that since the outcome was health care utilization, it implied that more care was always better.

Weissman and Epstein (1994) defined access as “the attainment of timely, sufficient and appropriate health care of adequate quality such that health outcomes are maximized.” An important contribution of this definition, mentioned in Healthy People 2010 (DHHS, 2001) is that it attempts to put access into perspective, as the means to a goal, that is, preserving and promoting health, not merely increasing health care utilization. Weissman and Epstein (1994) developed a conceptual model of access to reflect this definition. In their model, the determinants of access are characteristics of the patient and characteristics of the health system. Its main shortcoming is that it ignores characteristics of the social and political structure surrounding the individual. Additionally, it calls users “patients” and thus unnecessarily medicalizes the notion of health care access. Many healthy people are not patients, yet they need access to preventive services, such as immunizations and health education.

Over the years, Andersen’s conceptual model was revised by Aday and Andersen (1975), Aday et al (1984), and again by Andersen (1995). The latest version considers perceived and evaluated health status and consumer satisfaction as endpoints (Figure 1). The use of health services affects the

outcomes, but is not an endpoint in itself. Characteristics of the population, health behavior, and health practices are factors that determine use of health services. An important improvement of this model is that the outcomes may, in turn, affect the determinants of access. For example, perceived health status may affect need and health practices. Another important improvement of this model is that it explicitly includes a dimension that contains the system of health care and the external environment. They can affect health behaviors, health outcomes, and predisposing characteristics of the individual or population, such as income or education. The inclusion of these structural factors allows the researcher to focus on the characteristics of the health and social systems as able to be addressed by policies. Another improvement in Andersen's revised model is that the degree of mutability of factors affecting health and health care access is important. Some characteristics of individuals can be considered immutable, such as age, sex and race. Health beliefs are seen as moderately mutable. Characteristics of the individual that are enabling factors, such as availability of health insurance, are considered highly mutable. Characteristics that relate to the social structure, such as education, income, and racism, have low mutability, but the characteristics of the health system are more amenable to change.



**Figure 1**

**A framework for the study of access to health care**  
 From Andersen, 1995.

## 2. Measuring health care access

Ideally, if health status is the endpoint, access should be measured by indicators of health status (Aday et al, 1998). For example, Riedel (1998) proposes using successful birth outcomes and vaccine preventable diseases as indicators of access; Weissman and Epstein (1994) propose using mortality data, perinatal outcomes, stage at diagnosis of cancer, and perceived health status. However, in most cases this type of measurement is not practical or feasible. The event that should be avoided (for example, an infant death) may be rare, and a very large sample would be needed to make meaningful inferences (Weissman & Epstein, 1994). Additionally, it is generally difficult to know how important health care access is in determining health status, but it is by far less important than social structure and behavioral factors (Aday et al, 1998; Weissman & Epstein, 1994; Zambrana, 1996 a). This is even more relevant in the case of Latinos in the U.S., since many are immigrants. They were not born and raised in this country; therefore it is more difficult for the health system of the United States to determine their current health status. However, it is important to keep in mind that the ultimate outcome of health care access is to preserve or improve health status.

Andersen categorizes access in two dimensions, potential and realized. Potential access relates to the process of obtaining health care or, said differently, to the presence of enabling resources for health care utilization. Realized access refers to the care actually received (Aday et al, 1984; Andersen, 1995). Some authors include in the concept “access to care” only what has been defined here as “realized access” (Brown et al, 2000; Brown et al, 1999; Weissman & Epstein, 1994). They consider what has been defined here as “potential access” to be a determinant of access. This is really a semantic difference. In this dissertation, access will be considered both potential and realized.

There are several indicators commonly used to measure the different dimensions of health care access. Potential access may be measured as having health insurance (Aday et al, 1998; Aday et al, 1984; Andersen, 1995; de la Torre et al; 1999, Flores et al, 1998; Halfon et al, 1997; Solis, 1990) or as having a regular source of care (Aday & Andersen, 1975; Aday et al, 1998;

Flores et al, 1998; Halfon et al, 1997; Smith et al, 1996; Solis et al, 1990; Sonis, 1998; Zambrana, 1996 b). Some, like Treviño et al (1996), distinguish between private and public insurance because the benefits of each may vary greatly. Organizational and structural measures of potential access include convenience and accessibility. Convenience includes waiting time for an appointment, waiting time in the office, geographical distance to the source of care, scheduling options, and care missed or delayed because of financial reasons or waiting time. Accessibility includes availability of transportation, eligibility criteria for insurance, availability of health facilities within reach, availability of health care personnel, availability of care in a language understood by the consumer, and availability of staff culturally and linguistically similar to the population served (Aday et al, 1984; Aday & Andersen, 1975; Castillo, 1996; Flores et al, 1998; Giachello, 1996 a; Gray & Puente, 1996; Halfon et al, 1997; Kiefe, 1996; Riedel, 1998; Weissman & Epstein, 1994).

Realized care is frequently measured by the proportion of people seeing a physician in a period of time, usually the past year (Aday & Andersen, 1975; Aday et al, 1998; Cornelius, 1997; Hajat et al, 2000; Kiefe, 1996; Palacios & Sheps, 1992; Smith et al, 1996; Weissman & Epstein, 1994), the mean number of physician visits in a year (Aday & Andersen, 1975; Aday et al, 1998; Sonis, 1998), use of emergency rooms for primary care, and continuity of care (Weissman & Epstein 1994). Days of hospitalization, illness and disability have also been used as indicators of access (Treviño, 1985; Weissman & Epstein, 1994). However, the latter measures might be indicating “need” more than “access,” unless many other variables are taken into account. Though its importance cannot be denied, quality of care is less frequently used as an indicator of realized access, since its operationalization is difficult. It requires a more clinical setting and a narrow definition, such as the proper protocol to follow for a specific condition (McDermott et al, 1996). Additionally, the definition of what constitutes quality health care is likely to be different depending upon who states it. For the provider, it is likely that adherence to current protocols is very important to determine quality of care; for the consumer, the speed and politeness of medical staff might be more important.

Clearly, perceived health status is a measure of need that is affected by the social structure and by the beliefs and demographic characteristics of the individual consumer. However, according to Andersen (1995), provider evaluated need that might be considered more objective is also affected by the state of the knowledge in the health sciences and by the values guiding health standards and recommendations for health services utilization.

Satisfaction with services received, the subjective evaluation of the consumer, may be considered a measure of realized access, since it depends on the quality of care and is related to health status of the consumer, as explained by Aday et al (1984). It is usually measured by a single question, but often measured by several questions addressing dimensions such as waiting time, out of pocket cost, courtesy, medical information given, and overall quality of care (Aday et al, 1984; Aday & Andersen, 1975).

Indicators used to measure realized access to preventive care for adults include having a blood pressure determination, a Pap smear, a breast exam, and a mammography in the past year (Aday et al, 1984; Fulton et al, 1995; Martin et al, 1996; Pearlman et al, 1996; Suarez, 1994; Weissman & Epstein, 1994). Immunizations are used as a corresponding measure for children (Flores et al, 1998). This measure is better before age 5. After that age, children enter school and the proportion of immunized children rises to around 90% because most schools require complete immunizations (Aday, 1984).

Having a visit to the dentist in the past year is perhaps the most frequently used indicator of realized access to dental care. Usual source of dental care is also used often (Davidson et al, 1996; Palacios & Sheps, 1992; Smith et al, 1996). Other measures include ever seeking care and seeking care for preventive reasons (Ismali & Szpunar, 1990).

### 3. Determinants of health care access

Most research to assess equity in health care services has been based on the distributive justice paradigm (Aday et al, 1998). Distributive justice is based on liberal or individual values, whereas social justice is based on communitarian values. Social justice's goal is to take those actions that bring about the most good for society as a whole and is concerned with the physical,

social, and economic environments or structures that surround individuals and population groups. Schools, jobs, housing, income are all dimensions of the economic environment. Social capital, understood as family structure, social networks and voluntary organizations, are dimensions of the social environment. Aday et al (1998) say that “equity is concerned with health disparities and the fairness and effectiveness of the procedures for addressing them” (p. 200). While effectiveness is an empirical question, fairness is a normative one. The ultimate goal of public health and of equity is to improve the health of individuals and decrease disparities among population subgroups. Because non-medical factors play a large role in health disparities, the broader environment has to be considered. This leads to the consideration of equity within a social justice paradigm. Utilitarian theories are the foundation of public health’s social justice approach to the study of equity in health care. The concept of the common good is related to social solidarity. The ultimate goal of interventions is altering the structural dimensions that are at the root of inequalities in health and health care access.

The distribution of access to care according to predisposing, enabling, and need dimensions is a concern of distributive justice and social justice. From a social justice point of view, it is important to know whether access is equitable or not. Aday et al (1998) and Andersen (1995) define access as equitable when health care is available to all, and the characteristics that define need for services, such as age, sex, and health status, are the main determinants of health care utilization. This is the same point of view adopted by Healthy People 2010. In its second overarching goal proposes to eliminate health disparities. The document expresses commitment to equity in health care access:

“Healthy People 2010 is firmly dedicated to the principle that –regardless of age, gender, race, ethnicity, income, education, geographic location, disability, and sexual orientation– every person in every community across the Nation deserves equal access to comprehensive, culturally competent, community–based care systems that are committed to serving the needs of the individual and promoting community health.” (DHHS, 2001)

If access were equitable, improving health outcomes would require improving access for the population as a whole or changing other determinants of health that are not related to the health care system, such as the level of contaminants in the air or water. However, if the main determinants of health care utilization are social structure variables such as ethnicity, income, education or language, then access is not equitable (Andersen, 1995). Therefore, improvements in health status and satisfaction may be expected from removing barriers to access to the health care system for those groups that experience low access.

Several indicators show that access is not equitable. According to Riedel (1998), since the enactment of the Hill-Burton Act in 1946, availability of services and personnel has increased greatly, but their distribution throughout the U.S. is not equitable. Additionally, available services are often not culturally compatible with the population served.

Income and education appear to be the major determinants of access. People with higher socioeconomic status can pay for health insurance and/or health care, they may be more knowledgeable about their health care needs and options, and they may be able to better articulate demands for care. Possible solutions for this inequity include the development of a national health care system and the expansion of Medicaid eligibility criteria, among others (Brown et al, 2000; Weissman & Epstein, 1994). However, even if universal health insurance were available, there are indications that realized access would be inequitable.

Language and acculturation are frequently mentioned as factors influencing access. They relate to the cultural sphere, but cover it only in a limited way. Other cultural factors may include conceptualizations of health and disease and perceptions of what constitutes appropriate human interaction, timing, and quality of care (Fulton et al 1995, Pearlman et al 1992, Smith et al 1996). For this reason, it is important to consider the particular characteristics of the population under study. Cultural characteristics should not be considered a handicap, something that should be fixed to attain better access. Instead, the health care system should be modified to better match the population that uses or is expected to use the services.

Still, from a social justice point of view, potential access should be equally distributed among all members of society, and need for care should determine utilization. For example, a sicker person should have more visits to the doctor than a healthier person would. Finding an appropriate measure of need is not easy. Health care providers may feel it is best measured through current recommendations for care (Medicare Payment Advisory Commission, 1998), while users may define it differently. Age, sex, and health status are frequently used proxy measures of need. Health status can be evaluated by a provider, using measures such as medical severity index, use disability ratio, symptoms response ratio, and activity limitations (Aday & Andersen, 1975; Hajat et al, 2000). It can also be evaluated by the consumer, using measures such as perceived health status, for which several scales have been developed.

Potential access to health care in the U.S. is far from universal. Its most frequently mentioned determinants are financial or economical, especially income level and education (Andersen, 1995; de la Torre et al, 1999; Flores et al, 1998; Fulton et al, 1995; Halfon et al, 1997; Martin et al, 1996; Weissman & Epstein, 1994). Other related determinants of potential access are geographical location, employment status and whether or not the job provides insurance (de la Torre et al, 1999; Weissman & Epstein, 1994). Those living in the Eastern U.S. are more frequently insured than those living elsewhere (Weissman & Epstein, 1994). Age, sex and marital status are important, too, as younger adults, single people, and males are typically insured less often than older adults and females (de la Torre et al, 1999; Suarez, 1994; Weissman & Epstein, 1994). Ethnicity is related to potential access, even after accounting for differences in income and education (Aday et al, 1984; Fulton et al, 1995; Himmelstein & Woolhandler, 1995; Kiefe, 1996; Pearlman et al, 1996). Blacks and Hispanics face more barriers to access than non-Hispanic Whites (Aday et al, 1998). For immigrants, language, acculturation, and time spent in the U.S. are considered determinants of potential access (de la Torre et al, 1999; Flores et al, 1998; Fulton et al, 1995; Smith et al, 1996; Schur & Albers, 1996). It is expected that over time immigrants acquire jobs that provide insurance and learn how to make better use of the U.S. health system. However, researchers have found that when controls for socioeconomic status have been applied,

language has no impact on potential access to care (Halfon et al, 1997). Frequently used measures of these determinants include years in the United States (Sonis, 1998), language proficiency and preference, and a variety of acculturation scales (Negy & Woods, 1992). Other determinants of potential access that are “outside of the individual” include racism and discrimination (Giachello, 1996 b), rural residency (Himmelstein & Woolhandler, 1995) and organizational characteristics of the health system (Halfon et al, 1997, Weissman & Epstein, 1994).

As should be expected, if we follow Andersen’s 1995 model, potential access determines realized access (Aday et al, 1998; Aday et al, 1984). Insurance status, convenience of the service, and having a usual source of care determine both satisfaction and having a visit to the doctor (Aday et al, 1984; Giachello, 1996 a; Halfon et al, 1997; Himmelstein & Woolhandler, 1995; Suarez, 1994; Treviño et al, 1996; Weissman & Epstein, 1994). Having a source of care is also associated with greater compliance, continuity of care and satisfaction (Aday et al, 1984; Cornelius, 1997). Consumer satisfaction and utilization are related to and influence each other. In addition, potential access and realized access affect each other. Having a regular source of care is a predictor of both utilization of services and satisfaction with services. This is true when the source of care is a particular doctor or other health provider. However, when the regular source of care is a particular place, such as a clinic or office, rather than a person, the influence of this measure on satisfaction is lower (Aday et al, 1984). Conversely, a satisfied consumer is likely to make more use of the health system (Aday et al, 1984).

Other important determinants of realized access are age and sex; younger people and males have fewer contacts with the health system per year (Weissman & Epstein, 1994). Income and ethnicity also influence realized access. Health status should show influence on realized access of a curative nature, but not on preventive care.

## ***C. Definition of the population***

### 1. Demographic profile

The number of Latinos in the U.S. has increased from 22.6 million in 1990 to more than 35.3 million in 2000, according to preliminary results of Census 2000 (Grieco & Cassidy, 2001). This is an increase of 56% over 10 years; Latinos now represent 13% of the population of the United States (Grieco & Cassidy, 2001). Latinos are a young population. In 1998, the median age was 26.6 years, almost ten years younger than the median for the nation as a whole. Almost a third of Hispanics in the U.S. were under 15 years of age, and less than 5% were 65 years of age or older. Hispanic males outnumbered females, although the opposite was true among Whites and African Americans. This particular feature of the Hispanic population is due to the effect of migration: men tend to migrate ahead of women, and, in some cases, women never migrate out of their country of origin.

Latinos, as a group, are socioeconomically disadvantaged, although great diversity exists among Latino subgroups, as noted by Becerra and Zambrana (1985), and Nelson and Tienda (1997). According to 1990 Census data, only half of all Hispanics had finished high school and 3% attained a professional or graduate degree. The median Latino household income was \$20,000, just two-thirds of the median salary for the U.S. as a whole. Even people with college degrees typically had incomes lower than their White non-Hispanic counterparts (U.S. Census Bureau, 1998). In 1998, one-fourth of Latinos lived under poverty. Among families with children headed by a woman only, 58% were poor (U.S. Census Bureau, 2000 a).

According to U.S. Census information (1998), Hispanics are geographically concentrated on the West and East coasts, in Florida and in Illinois. In 1990, nine states (California, Texas, New York, Florida, Illinois, New Jersey, Arizona, New Mexico, and Colorado) accounted for 84% of the Hispanic population. However, the number of Hispanics, and in many cases, the proportion of the population that is Hispanic, has been increasing in almost every state of the Union. In 1990, almost two-thirds of Hispanics in the U.S. were of Mexican origin, 13% were Puerto Rican, 5% were Cuban, and 12% were

from Central or South America. Their origin determined their location in the U.S.: most Latinos in the Southwest could trace their origins to Mexico and Central America. Most Hispanics in Florida were Cubans, and most in the East were Puerto Rican. Hispanics in Washington, D.C. and in Illinois were of mixed origins (U.S. Census Bureau, 1998).

## 2. Definition of Hispanic or Latino

Who is Hispanic? Sometimes it is not easy to answer this question. There are several definitions of Hispanics. The Office of Budget Management introduced this category in 1978 to include persons “of Cuban, Mexican, Puerto Rican, South or Central American, or other Spanish culture or origin, regardless of race”. (Office of Budget Management, 2001). Although most authors use this definition (Becerra & Zambrana, 1985; Marin, 1989), some exclude people from Spain, as it is a European country. Most, but not all, do not consider people from the Philippines to be Hispanics. Many researchers, either explicitly or implicitly, include only Spanish speakers in this group, leaving out Brazilians and Portuguese. The question about whether Brazilians are Latinos is not easily answered (Castillo, 1996). Brazilians share many traditions and history with Spanish-speaking Americans. However, they are unique as speakers of a different language. (Becerra & Zambrana, 1985; Fox, 1996; Marin & VanOss Marin, 1991).

Definitions are not always clear and even the label itself, “Hispanic,” is contested (Fox, 1996; Goldsmith, 1993; Gonzalez, 2000). Some Latinos prefer to be called Hispanic, or Hispanic American, and others prefer to be called Latino or Latin American (Flores et al, 1998; Marin & VanOss Marin, 1991). In the West, many people of Mexican origin prefer to call themselves “Chicanos,” or *Raza*, that literally means “race” and alludes to the “cosmic race,” a concept proposed by the Mexican José Vasconcelos (Chavira-Prado, 1992; Gonzalez, 2000; Stavans, 1995). This concept was relatively recently supported by nationally recognized figures, such as Hayes-Bautista (1980). Hayes-Bautista wants to make clear that discrimination is related to being Indian, not White Spanish. He goes on to say that even “Latino” or “Latin American” are better than “Hispanic.” Hayes-Bautista agrees with others who believe that “Latino” is

a more inclusive label, as it may encompass people of African and even Asian descent (Flores et al, 1998). Stavans (1995) disagrees and claims that the origin of the word “Latino” is in “Latin,” and means from a place in Italy. The quest for an all-inclusive term has taken many forms. From another perspective, Cuello (1998) proposes use of the word “Latinoa,” to avoid gendered terms, such as “Latino” or “Latina.” Nationally, there is no agreement among Latinos over which label is best. Many researchers use the labels “Hispanic” and “Latino” interchangeably, independent of their personal preferences, as it is practical to use names that are recognized by everybody (Gonzalez, 2000; Nelson & Tienda, 1997; Stavans, 1995; Trueba, 1999). In this dissertation, the words “Hispanic” and “Latino” are used as synonyms.

Attempts to define the Latino group create problems. An interesting example is one provided by Carramiñana (2000). In an effort to diversify its faculty, a university in Chicago offered a \$30,000 incentive for a new Latino or African American professor. A South African born white male who had become a U.S. citizen claimed to be an African American. He received the award, but defeated the purpose. As a result, the university tried to develop a consensus about the definition of each ethnic group. There was a passionate debate about who was a Latino. For practical reasons, they needed to define Latino ethnicity clearly and decided to use a definition with two dimensions. First, the person had to identify him or herself as Latino/a and state the reason for that identification. This was a necessary but not sufficient condition. Second, the person had to meet certain characteristics. For example, children of U.S. Army personnel born while stationed in Latin America were not eligible to be considered Latinos. This part of the definition was the most difficult to establish and the final decision was not unanimous. A third, dimension, proposed but not accepted, was ethnic identification by others.

Most Hispanics share at least some of the following characteristics: they speak Spanish, they have a similar colonial history and they have similar cultural traits related to Iberian ancestry. However, Hispanics are a heterogeneous group of people whose origins might be in several countries of Latin America or may belong to families established in the U.S. for generations. Racially, Hispanics may be Native American, Black, White, Asian or, more

commonly, a mixture of two or more races (Fang et al, 1997; Fox, 1996; Marin & VanOss Marin, 1991). Hispanics in the U.S. can be broadly divided into six groups: Mexicans, Puerto Ricans, Cubans, Central Americans, South Americans, and Others. Several authors, such as Castillo (1996), Fox (1996), Goldsmith (1993), and Marin and VanOss Marin (1991), include Hispanics born in the U.S in the last subgroup. These subgroups have several different cultural and socioeconomic characteristics. Cubans tend to have a better socioeconomic status than other groups; Puerto Ricans are legal U.S. citizens who can vote and are entitled to receive public assistance. Hispanics from the Southern Cone of South America are more likely to be white; those from Puerto Rico and some Central American and Caribbean countries are more likely to be White or Black; and those from Mexico, Guatemala or the Andean countries are more likely to be *mestizo* (mixture of White and Indian) or Indian. Some Latinos were born in the U.S.; others are immigrants. Some Hispanics have an uncertain migratory status; some do not (Chavez et al, 1992).

The main path of migration for Latinos depends on their country of origin. Almost the entire present-day U.S. Southwest was once Mexico. After the Treaty of Guadalupe-Hidalgo in 1848, Mexicans living in those territories had the option of becoming U.S. citizens. Therefore, they were never “immigrants.” In the mid 1960s, the *Bracero* Program allowed thousands of Mexican agricultural laborers to work in the U.S. When the *Bracero* Program was canceled in the mid-1960s, illegal immigration from Mexico escalated. Puerto Rico has been as U.S. territory since the Spanish American War in 1889. In 1917 Puerto Ricans acquired U.S. citizenship, and they have been living in the U.S. ever since. However, U.S. labor shortages in industry in the mid 1950s attracted a great number of Puerto Ricans to the mainland. Even though small pockets of Cubans lived in the U.S. early this century, especially in New York and Tampa, the greatest influx of Cubans occurred in the early 1960s, when many fled the Castro regime. Many of those immigrants were well educated and even wealthy. Later immigrants, arriving in the 1980s, with the Mariel boatlift, generally had fewer years of formal schooling. Still today, Cuban refugees arrive, but in smaller numbers. There were few immigrants from South and Central America before the 1980s. At that time, political upheavals, internal

wars and profound economic crisis drove thousands of Central and South Americans to the U.S. Many of them are still trying to find a stable way to stay in the U.S. (Gonzalez, 2000; Hajat et al, 2000; Trueba, 1999)

Fang et al (1997) describe Hispanics as a “heterogeneous group of racially and ethnically different individuals who vary markedly in socioeconomic and demographic characteristics.” Becerra and Zambrana (1985), Casas (1992), Marin and VanOss Marin (1991), Nelson and Tienda (1997) also highlight Latinos’ heterogeneity, recognizing that differences among subgroups may have implications for public policy. This raises the question, Are Hispanics a single distinct group in the U.S.? Padilla and Salgado de Snyder (1992) believe that “Hispanic” is only a label used to group together for statistical purposes people who have little in common. Nelson and Tienda (1997) believe that they are a group that reflects only an income and social class division. A few authors, such as Marin and VanOss Marin (1991) believe that they comprise a group that comes “naturally” together.

### 3. Cultural profile

What are the characteristics that would identify the Latino group? Marin (1989) says,

“Although there are important socio-demographic differences among the various Hispanic subgroups according to country of origin, educational attainment, and acculturation level, all Hispanics seem to share core cultural values that differentiate them from other cultural groups” (pp. 413-414).

Many authors talk about some cultural values or characteristics of Latinos. They identify several cultural traits that, individually, are not exclusively Latino. However, these authors believe that when those characteristics are put together, they form a profile of Latino cultural values (Bassford, 1995; Casas, 1992; Castillo, 1996; Furino & Sumaya, 1992; Gonzalez, 1997; Marin & VanOss Marin, 1991; Pérez-Montijo et al, 1996; Rosaldo, 1997; Saunders, 1954). This does not mean that all Latinos behave according to these traits, or that those who do, do so in every instance. Cultural values are related to the “ideal” or “imagined” behavior of the group. A brief description of the most

commonly mentioned cultural traits, as explained by Marin 1989, Marin and VanOss Marin 1991, Ruiz 1985, follows.

*a. Simpatía* is a Spanish word not readily translated, and means the need for behaviors that promote smooth and pleasant social relations. Non-confrontational attitudes are preferred over aggressive and assertive ones.

*b. Familism* is a strong identification with the family, especially the extended family. Individuals have perceived obligations to members of the family, rely on each other for help and support, and perceive relatives as behavioral referents.

*c. Allocentrism*, communalism or collectivism is an emphasis in the needs and objectives of the group, rather than on those of the individual. Hispanics view non-competitive, interdependent relationships with other members of the community as ideal.

*d. Personalismo* is the preference for interpersonal relations over professional ones, especially with people of the same ethnic group. Some authors describe *personalismo* as the preference for a “formal friendliness” in interpersonal relationships.

*e. Power distance* is related to respect and includes some special deference to people who are older or more educated. In addition, people of lower education or younger are to be treated with “dignity” and “respect.” Power distance, in many instances, calls for the use of a formal form of “you” (*usted*), instead of the informal one (*tú*).

*f. Small personal space* refers to the physical closeness to which Hispanics are used. They feel comfortable standing closer to the person they are talking to, than Anglos do. They also tend to touch each other and hug.

*g. Time Orientation.* Hispanics are present-oriented and their perceptions of time and punctuality are more flexible than those of Anglos.

In many cases, these traits are mentioned without anchoring them in specific research. For others, the “vestiges of Spanish culture” are not very important as commonalities, but class is. Nelson and Tienda (1997) and Zambrana (1996 b) consider Latinos to be a group with something in common as long as they are socioeconomically disadvantaged.

There are two important questions that need to be answered when we talk about cultural traits. First, is it true that these characteristics are exclusive

of Hispanics? Claiming this, is an illusion. This question cannot be answered, unless we studied all cultural groups, an impossible undertaking. It is likely that other groups share several or all of these characteristics. Second, is it true that all Hispanics share these characteristics? As all generalizations, this is not a good one; it can be the result of applying stereotypes, and may lead to more stereotyping (Rivero, 2000). Valid questions are: what characteristics have been found commonly among Latinos? Can those claims be documented by research findings?

After studying literary texts, Stavans (1995) believes that Latinos are united by common characteristics, and anchored in history, such as Roman Constitutional law and romance languages. Some researchers found recurrent themes among Latinos of different origins. For example, Benmayor et al (1997), who worked with a literacy program in New York City that served Puerto Rican women, found that dignity, *respeto* (respect), *cariño* (love), *apoyo* (support), *cooperación* (cooperation), and *confianza* (trust) were recurrent themes. Additionally, they found that women's commitment to their families was a strength, and that collectivism, or working towards a common goal, was instrumental in both developing unique individual capacities and intensifying a sense of belonging to a group. Women described the importance of learning literacy skills not only as a personal goal, but also as contributing to the betterment of the Latino community. Singer (1993) in Hartford, Connecticut, found that a program to prevent AIDS that stressed the ideas of *reunión* (reunion), *responsabilidad* (responsibility), *respeto* (respect), *comunidad* (community) and *personalismo* was effective for Latinas. Drawing from his research mainly on Mexican Americans, Trueba (1996) says that family is the core of Latino values, as is the formation of networks that support communal goals. Many of the values related to family, community, respect and inclusion of older people are at odds with the individualistic independence and culture of youthfulness in U.S. society, as pointed out by Bassford (1995).

#### 4. The Latino community in the U.S.

Even though Hispanics share similar historical and cultural roots and several Latin American intellectuals have dreamed of a united Latin America for

more than a century, authors such as Fox (1996), Nelson and Tienda (1997) and Oboler (1997) believe that it is in the U.S. that Latinos become a group. The Census Bureau groups them to count them. Media and businesses find it more profitable to direct advertising to the broader Latino market. Latinos themselves find that being together makes more sense if they are in any form to affect U.S. policy (Fox, 1996). After immigration, most Hispanics experience similar difficulties in adjusting to the U.S. system and similar discrimination (Oboler, 1997). There is a “feeling of mutual recognition” due to shared cultural values that help to make this population a distinct group (Fox, 1996). Latinos tend to project their imagined communities at public celebrations (Rosaldo & Flores, 1997). This same type of community formation after migration has been reported among other groups in the U.S., such as Jewish immigrants (Silverman, 1989).

Trueba (1999) reports that some Anglos believe that Latinos are not able to assimilate into U.S. society. However, he believes that Latinos choose not to join the so-called melting pot. According to Fox (1996) demographic pressure and enhanced mass communications –including the existence of four Spanish language television networks– are important factors in the creation of an ethnic group. Hispanics in the U.S. do not try to separate themselves from the U.S., but to find a space where they can be themselves, where they can validate their culture and where their rights are recognized. This is what Flores and Benmayor (1997) call “cultural citizenship.” It is the way people organize, their values, their beliefs, and their practices, based on a sense of cultural belonging. Different Latino subgroups undergo amalgamation through intermarriage and shared knowledge about each other’s music, food, tradition, and language (Gonzalez, 2000; Silvestrini, 1997; Trueba, 1999). Elements of U.S. and Latin American culture are mixed, and new cultural forms are created (Flores WV a, 1997; Gonzalez, 2000; Rocco, 1997). However, this process does not occur without conflict. Sometimes new identities clash with old ones. Johnson (1990) studied Census 1990 Hispanic origin question data and concludes that there is no single dimension of meaning underlying the responses to the Hispanic origin question. He argues that

“...in pluralistic situations, ethnicity is a highly factual characteristic: ascribed at birth, hard to change, and verifiable by reference to manifest and commonly recognized signs and symbols”. (p. 58)

However, in assimilating situation, such as the situation of Hispanics in the U.S.,

“ethnicity tends to be subjective, diffuse (possibly attaching to more than one ethnic label), capable of change within the individuals’ life (possibly changing from one measurement to the next), continuous rather than discrete (varying in intensity) and not subject to verification using an external standard of accuracy.” (p. 58)

At the same time Latino ethnicity changes within individuals and within the group, Latinos attempt to change their environment and make it more receptive to their culture (Rosaldo, 1997; Rosaldo & Flores, 1997; Flores WV, 1997 a). In this way, they are influencing U.S. society, just as other groups before have done (Fox, 1996; Gonzalez, 2000).

Oboler (1997) wrote that the meaning and social role of Hispanic identity “must be found through exploring the specific context of U.S. society that fostered the emergence of this ethnic label as an ideological construct.” (p. 32) It is not a simple collection of traits; it is a social construct that emerges after immigration (Fox, 1996; Gonzalez, 2000; Jones-Correa & Leal, 1996; Nelson & Tienda, 1997; Oboler, 1997; Stavans, 1995; Trueba, 1999). Denying the existence of a Hispanic ethnic group could only curtail the political influence of this group, and its many disadvantaged members.

After immigration, the commonalities among Latinos tend to override the differences, although the formation of a group identity is a slow process that is by no means complete (Fox, 1996; Nelson & Tienda, 1997; Ruiz, 1985). Latinos are an ethnic group in formation, an imagined community (Fox, 1996; Gonzalez, 2000; Oboler, 1997; Rivero, 2000; Rosaldo & Flores, 1997; Stavans, 1995; Trueba, 1999). Ethnic identification is not static. It is continually being defined, and it is a state of continuous negotiation (Keefe, 1992). The Latino community is a collective creation in process and nobody knows clearly what its final shape will be.

#### ***D. Health status of Latinos***

At the national level, population data from the Medical Expenditure Panel Survey (MEPS) of 1996 (Kass et al, 1999) and from the National Health Interview Survey (NHIS) 1992-1995 (Hajat et al, 2000) show that between 17-18% of Hispanics of all ages report they are in poor or fair health. According to NHIS data, 16.1% of non-Hispanic Blacks and 9.9% of non-Hispanic Whites report fair or poor health. For all ethnic groups, females report poor or fair health more frequently than males do (Marin & VanOss Marin, 1991). Data collected by the University of Wisconsin in the National Survey of Families and Households (NSFH) show that Hispanics and African Americans are both significantly more likely to report poor health status than non-Hispanic Whites (Ren & Amick, 1996). There are also differences between subgroups. For example, Mexicans were significantly more likely to report poor health status than non-Hispanic Whites (OR = 1.77; CI: 1.7 -2.47). Results for Puerto Ricans, Cubans and Other Hispanics were non-significant. However, Puerto Ricans were the only group significantly more likely to report activity limitations than non-Hispanic Whites (OR=2.14; CI: 1.31-3.48) (10). A similar result was obtained from the NHIS 1992-1995 (Hajat et al, 2000).

The main causes of death among Latinos are heart disease and cancer. However, according to Abraído-Lanza et al (1999), Balcazar et al (1999), Bassford (1995), and Fang et al (1997), the rates of death from these diseases are lower among Hispanics than among the population of the U.S. as a whole, as are death rates in general. Lower mortality rates may be due to at least to two factors. Those who immigrate tend to be healthier than those who do not immigrate, and “salmon bias”, the tendency of immigrants to return to their home country as they age and thus not be counted as deaths in the U.S. Abraído-Lanza et al set out to study those biases using 1998 Current Population Survey (CPS) data linked to death certificates. They found that Cubans and Puerto Ricans, who typically do not leave the U.S. at the end of their lives, experience a mortality rate smaller than the general population of the U.S. Further, U.S. born Latinos, unaffected by the “healthy migrant” bias, also have a small mortality rate. Infant mortality and low birth weight are not a

particular problem, except for among Puerto Ricans, whose rates are similar to those of African Americans. The other groups have infant mortality rates similar to those of non-Hispanic Whites. These differences have yet to be fully explained. Some researchers have called it a paradox that this socio-economically disadvantaged group experiences infant mortality rates that are relatively low (Reichman and Kenny, 1998).

Hispanics have higher mortality rates than the general U.S. population due to accidents, homicides, diabetes and liver disease, as reported by Fang et al (1997) and Vega and Amaro (1994). Balcazar et al (1999) report that cancer of the breast is growing more rapidly among Latinas than among other women. Diabetes is very prevalent among Latinos, especially among those of Mexican and Puerto Rican origin (Brown et al, 2000; Oxendine, 1999; Ren & Amick, 1996). The prevalence of complications of diabetes is particularly high among Mexican Americans (Oxendine, 1999). Hispanics are overrepresented in the number of cases of various infectious diseases, such as tuberculosis, brucellosis, rubella and Hansen (Centers for Disease Control and Prevention (CDC), 1998). In 1996, 21% of the people with tuberculosis and 60% of the people with brucellosis were Latinos. In addition, Latinos are the group in which AIDS is increasing most rapidly.

**Table 1**  
**Selected notifiable diseases in Hispanics, 1996**

| Disease      | Number of cases | Percent of all U.S. cases |
|--------------|-----------------|---------------------------|
| Brucellosis  | 67              | 60                        |
| Rubella      | 132             | 55                        |
| Hansen       | 35              | 31                        |
| Tuberculosis | 4,533           | 21                        |
| AIDS         | 10,865          | 16                        |

Source: CDC 1998.

Qualitative data on Hispanics, such as those collected by Ludwig-Beymer et al (1996), frequently mention oral health problems as important in this community. Quantitative data confirm that belief. Davidson et al (1996) found that the percentage of decayed and missing teeth were higher among Latinos than among non-Latino Whites.

**Table 2**  
**Percentage of missing or decayed teeth in Hispanics and non-Hispanic Whites**

| Ages                        | White |       | Hispanic |       |
|-----------------------------|-------|-------|----------|-------|
|                             | 35-44 | 45-74 | 35-44    | 45-74 |
| Percentage of decayed teeth | 1.2   | 0.6   | 2        | 1.7   |
| Percentage of missing teeth | 2.5   | 7.8   | 2.7      | 10.1  |

Source: Davidson et al, 1996.

When it comes to mental health, Latinos experience frequent social isolation and mental health problems, such as anxiety and depression. These problems are heightened by the immigration experience (Golding & Baezconde-Garbanati, 1990; Rogler, 1983). Abraído-Lanza et al (1999) and English et al (1997) argue that acculturation or assimilation into U.S. culture has both positive and negative consequences. More acculturated Hispanics eat less fat, but also less fiber. They engage in more exercise activities, but according to English et al (1997) and Bassford (1995), they also smoke more, abuse more drugs and consume more alcohol. Acculturated women take up smoking, a habit rare among Latin American women. Goslar et al (1997) found that the blood pressure of Mexican-American women increased with acculturation. Teenage pregnancy rates increase and the age of first sexual intercourse for both males and females decreases with acculturation (English et al, 1997).

## ***E. Access to health care for Latinos in the U.S.***

### 1. Potential access to health care

Hispanics encounter more barriers to medical and mental health care than any other subgroup in the U.S. (Treviño et al, 1996). They are the ethnic group most likely to be uninsured. According to Current Population Survey (CPS) data, the proportion of uninsured people in the U.S. has grown at the national level, from 25.7% in 1979 (Burciaga Valdez et al, 1993) to 33.5% in 1996 (Brown et al, 2000). Data from the 1998 CPS show that 37% of all Latinos nationwide are uninsured, compared to 23% of African Americans and 14% of non-Hispanic Whites (Brown et al, 2000). The proportion of uninsured Hispanics has increased since 1966, and the proportion of uninsured African Americans has remained relatively stable. Other studies confirm these findings (Treviño et al, 1996; Kiefe & Hyman, 1996). Data from the National Health Interview Survey (NHIS) 1994-1995 indicate that 34.5% of Hispanics between the ages of 18 and 64 are uninsured, compared to 14.4% of non-Hispanic Whites (HRSA, 1999). MEPS data from 1996 show that almost 30% of Hispanics do not have a regular source of care, compared to 20% of African Americans and 15.5% of non-Hispanic Whites (Kass et al, 1999). Analyzing data from the 1995-1996 NHIS, Brown et al (2000) reported similar findings: 26% of Latinos between the ages of 18 and 64 have no regular source of care, compared to 15% of non-Latino white adults of the same age group.

Data from the Medical Expenditure Survey (MEPS) of 1996 show that 45.1% of Hispanics between the ages of 16 and 44 who are working do not have insurance through their job. The corresponding numbers for African American and non-Hispanic Whites are 34.0% and 22.6%. Data from the 1998 CPS show that only 43% of Latinos between the ages of 0 and 64 are insured through their job or through the job of a family member (Brown et al 2000). It is likely that Hispanics show such a low frequency of insurance through jobs because they tend to work in informal jobs, to have an unstable migratory status, to be unskilled workers, and to have wages too low to afford private insurance (Brown et al, 2000; Health Resources and Services Administration (HRSA), 1999; Kass et al, 1999). Analyzing data from the NHIS from 1989 and 1990, Thamer et al

(1997) found that foreign-born individuals over 18 years old were twice as likely as U.S.-born individuals to be uninsured (26.2% and 13%, respectively). Foreign-born Hispanics were the group most likely to be uninsured (40.8%). Among U.S.-born individuals, Hispanics were the ones most likely to be uninsured (24.8%). Using logistic regression, Thamer et al found that Hispanics, foreign or U.S.-born, had a lower probability of being insured than U.S.-born Whites, even after controlling for sociodemographic characteristics, health status and health utilization. Another important finding was that among foreign-born Hispanics, length of residence in the U.S. increases the probability of having health insurance. This study included people 18 and older and no distinction was made between Hispanic subgroups. This poses a problem when interpreting the data, because Hispanic subgroups differ in socioeconomic and legal characteristics. Mexicans are known to have a lower proportion of insured individuals than any other Hispanic subgroup (Brink, 1994). If data were analyzed by ethnicity, the differences might be determined to be greater.

**Table 3**  
**Potential access measures at the national level by race/ethnic group**

|                     | No health insurance | No job related insurance | No usual source of care |
|---------------------|---------------------|--------------------------|-------------------------|
|                     | All ages            | Ages 16 –64              | All ages                |
| Hispanics           | 33.5%               | 29.6%                    | 54.9%                   |
| Non-Hispanic Blacks | 22.0%               | 15.2%                    | 34.0%                   |
| Non-Hispanic Whites | 13.1%               | 15.5%                    | 22.6%                   |

Source: Kass et al (1999)

Children have relatively better access to care than adults do, but 1998 CPS data show that 29% of Hispanic children under 18 are uninsured,

compared to 19% of African American and 11% of non-Hispanic White children (Kass et al, 1999). Other surveys validate this finding. According to the 1196 MEPS, 27.7% of Hispanic children under 18 are uninsured, compared to 17.6% of African American and 12.2% of non-Hispanic White children (Kass et al, 1999). Similarly, data from the NHIS 1994-1995 indicate that 25.8% of Hispanic children under 18 are uninsured. The comparable figure for non-Hispanic Whites is 11.7% (HRSA, 1999).

Weinick and Krauss (2000) also studied data of the 1996 MEPS. They found that among Hispanic children, 17% have no usual source of care, compared to 12.5% of non-Hispanic Black children and 6.0% of non-Hispanic White children. The influence of ethnicity over source of care persisted even after many demographic variables were included in the analysis. Additionally, they found that those children whose parents were interviewed in English were 2.6 times more likely to have a regular source of care than those whose parents were interviewed in Spanish.

There is a relationship between children's health insurance and income. Hispanics have low income as a group, and families with children are more likely to be under poverty: 20.6% of two-parent families with children and 58.2% of female-headed families with children are poor (U.S. Census Bureau, 1998). Health insurance is less frequent among those with lower income (Brown et al, 1999; Kass et al, 1999). In addition to insurance availability, type of insurance is also important to access certain services. Almost half of insured Latinos have public insurance only, compared to less than 20% of non-Hispanic Whites (Kass et al, 1999).

Immigration status affects access to health insurance. Brown et al (1999) found that non-citizen children of non-citizen parents are less likely to have health insurance than citizen children of non-citizen parents. The latter are less likely to have health insurance than citizen children of citizen parents. This pattern repeats itself for parents of all educational levels, even though nine out of ten children of immigrant families have at least one working adult in their family. Among children in immigrant families, Latinos are the ones that are least likely to have health insurance. Among Latinos, 56% of children of immigrant families are uninsured, compared to 25% of children of non-

immigrant families. Only 10% of children in non-immigrant U.S. families are uninsured. There are obvious implications for the future of the U.S. if the health of immigrant children is neglected. One-fifth of children are immigrants, and they represent a good portion of the next generation's workforce.

## 2. Realized access to health care

Population data from NHIS 1994-1995 show that Latinos are the group whose members are the least likely to have seen a physician in the past year (17%, compared to 11% for non-Hispanic Whites) (HRSA, 1999). Data derived from the 1992-1995 NHIS data show that more than a quarter of Latinos (27.3%) had not seen a doctor in the past year (Hajat et al, 2000). Lack of access to a regular source of care may be the reason why Hispanics tend to rely more on emergency room services for routine care than non-Hispanic Whites (9.9% and 4.4%, respectively) (Cornelius, 1997). Increased use of emergency services for non-emergency situations leads to higher cost of health care (Riedel, 1998). Most studies that separate Hispanics by subgroup have been conducted on the West or East Coasts and/or in Chicago, where there are services for Hispanics. Studies tend to be limited to a particular Hispanic group, such as Mexicans, and also restricted to subjects with Spanish surnames.

Hispanics also have a low frequency of dental care visits: 58% of Hispanics, compared to 39% of non-Hispanics Whites, did not visit a dentist in the past year (Davidson et al, 1996). This is of particular concern given that oral health status of Latinos is not optimal, and points to an unmet need.

**Table 4****Realized access measures at the national level by race/ethnic group**

|                        | No visit to the doctor in the<br>past year<br>Ages 18-64 <sup>a</sup> | No visit to the dentist in the<br>past year<br>Ages 35 –44 <sup>b</sup> |
|------------------------|---|---|
| Latinos                | 17.0%   | 57.8%   |
| Non-Hispanic<br>Blacks | 13.0%   | n.a.  |
| Non-Hispanic<br>Whites | 11.0%   | 33.8%   |

<sup>a</sup> HRSA 1999<sup>b</sup> Davidson et al 1996**3. Determinants of health care access**

Overall, 15.1% of Hispanic families report problems in access to health care, compared to 9.9% of non-Hispanic Black families and 11.4% of non-Hispanic White families (Kass et al, 1999). Factors of the population that influence access are age, sex, marital status, occupation, income, national origin and time in the U.S. Financial barriers include low income leading to lack of insurance and inability to meet co-payments. Convenience barriers are frequent, as Hispanics tend to live in underserved areas where health services are scarce. Often, hours of operation of clinics are not compatible with work hours, and there is lack of transportation and child care. In addition, perceived health status may influence access: a healthier person may seek care less frequently than a sicker one (Aday et al, 1984; Schur & Albers, 1996; Sonis, 1998; Thamer et al, 1997; Treviño et al, 1996).

Nationally, Hispanics use preventive services less than non-Latino Whites, and sometimes, less than non-Latino Blacks (Nápoles-Springer et al, 1996). However, the pattern of use of preventive services is not uniform to all Latinos. For example, Bassford (1995) found that Hispanics use preventive services less than other groups, and among Hispanics, Mexicans use preventive services the least. Most studies on preventive services relate to use of Pap

smears and/or mammograms. Pearlman et al (1996) analyzed data from the 1990 NHIS and found that ethnicity was not a significant predictor of mammography non-use, but that income under \$50,000 and living in the South were.

Data from the 1987 National Medical Expenditures Survey (NMES) reveals that Latinos use preventive services less than non-Latino Whites. Data from the NMES of 1992-1995 (Himmelstein & Woolhandler, 1995) indicate that Hispanic and Black women are less likely to have had a mammogram than non-Hispanic White women. Only 38.3% of Hispanic women and 37.8% of Blacks had a mammogram, compared to 47.7% of non-Hispanic Whites. According to the same study, Hispanic children were more likely to have incomplete immunizations (47.6%, compared to 26.3% of non-Hispanic Whites).

Martin et al (1996) studied NHIS data from 1987 to 1992. They found that the proportion of women who used Pap smears and mammograms had increased among all ethnic and racial groups. However, socioeconomic variables remained the main predictors for lack of mammograms and Pap smears. The results of their logistic regression showed that women with high school or less than high school education, and those with no usual source of care, had significantly lower odds of getting a mammogram or a Pap smear than their counterparts with more education and/or a usual source of care. Additionally, women with income below poverty, those with income to 300% of the poverty line were less likely to have ever had a mammogram than those with higher incomes.

Smith et al (1996) showed, using multivariate logistic regression, that in McFarland, California, children who had public insurance were significantly less likely to miss their checkups, than those with no insurance at all. The other important predictor of having a doctor's visit was poor or fair health and availability of transportation. They also found that income and insurance were both significant determinants of dental care.

Polednak (1996) studied Latino women in Long Island and Connecticut to elucidate the factors that predict use of Pap tests. Using logistic regression, they found that education and language of interview were significant predictors for having a recent Pap test. They controlled for age, insurance status, marital

status and area of residence. However, they did not include income in their equation, as they considered it to be too similar to education. A different model that contained income and not education showed that the odds ratio for income were non-significant.

In Rhode Island, Fulton et al (1995) found that the proportion of Latinas who got Pap smears or mammograms in the past year was lower than the correspondent proportion of low income non-Hispanic White or Black women. Latinas were less likely to perceive themselves to be at risk for breast cancer, to consider mammography safe, and to believe health care was important. When they controlled for demographic variables, the factors that remained significant predictors of use of screening for breast cancer were the recommendation of the provider, perceived effectiveness of mammography and perceived cost of mammogram. However, Latinas tended to be uninsured and providers tended to recommend screening less frequently to them than to other groups.

Treviño et al (1996) studied a random sample of Mexican Americans in San Antonio, Texas, and found using bivariate statistics that use of health services was determined more by having health insurance than by health care needs. Using logistic regression on data of the HHANES, Solis et al (1990) found that health insurance, regular source of care, and travel time determined utilization of screening services, when controlling for age, education and income. Language was a less strong predictor of utilization and was statistically significant only among Mexican Americans and Cuban Americans.

It has been argued that low health care access levels for Hispanics are only a result of their low socioeconomic status and educational attainment. However, while education and income are important, some authors believe that even if universal health insurance were available, Hispanics would still face many non-financial barriers to health care. Said another way, Hispanics would face cultural barriers to health care (Schur & Albers, 1996). Language is one of the most important barriers to health care access mentioned in the literature. Schur and Albers (1996) used data from the National Medical Expenditure Survey to assess the role of language in health care use by Hispanic adults. They found no statistical difference in the mean number of visits to the doctor among Hispanics by language spoken, but they failed to control for satisfaction

with the care received and sociodemographic variables. However, many of the Hispanics who did not speak English had a doctor who did not speak Spanish, an obvious communication problem. This would represent an “access” problem, because even when the visits take place, the result of a clinical encounter with such difficult communication is uncertain. Data from the 1994-95 NHIS indicate that only 44% of Hispanic adults are satisfied with their care, compared to 60% of non-Hispanic Whites (Thamer et al, 1997). In Boston, a clinic-based study found that language was the most important cultural barrier to care (Flores et al, 1998). Although their sample included only parents of children who were already getting care, 11% of parents said that health providers didn't understand their culture. (What exactly these parents meant by “culture” is not explained). It is likely that among those who have not accessed healthcare, cultural barriers are more significant.

Cultural barriers to health care include discrimination and differences between Hispanics and U.S. health providers in their understanding of health, disease, and proper care (Rotschild, 1998). Latino subgroups may have diverse concepts of disease and proper treatment; these frequently do not coincide with mainstream Anglo thinking (Moreno et al, 1997; Ruiz, 1995; Ruiz, 1985). As a culture, Latinos tend to rely more on personal alliances and friendship than on the “system of health care,” which might be perceived as impersonal. They might find the system of health care in the United States to be incomprehensible and bureaucratic (Goldsmith, 1993). Latinos may find the United States culture to be insensitive to their culture. For example, Latinos value placing the needs of others ahead of the needs of oneself and being non-competitive. Latinos identify these features of cooperation and concern with the health of others as strengths of the community as they relate to health care (Ludwig-Beymer et al, 1996). These characteristics may be perceived by Anglos to be signs of subservience and passiveness (Castillo, 1996). Also, some attitudes valued by Latinos may be considered to be inappropriate by the dominant culture in the United States.

Acculturation has been studied as a variable that may determine not only health outcomes, but also health care access. Acculturation is more than just “learning the language”; it involves a whole range of belief, behavior and

lifestyle changes. As related to health outcomes it has been found to interact with other variables such as education and socioeconomic status, (Balcazar et al, 1995; English et al, 1997; Ludwig-Beymer et al, 1996; Rotschild, 1998). People of communities that are undergoing a transitional period (becoming acculturated) are likely to exhibit beliefs that are not completely consistent with each other (Moreno et al, 1997). Differences in the construction of meanings can affect the way health care and health promotion are perceived. For example, Moreno et al found that most Latinos might not benefit from preventive messages developed for the general population not only because of language problems, but also cultural differences. One problem they identified in promoting healthy lifestyles among Latinos was that the word “prevention” was equated with “avoidance.” Therefore, for example, "increasing" physical activity was not perceived as “prevention” (Moreno et al, 1997).

Providers that are culturally similar to the patient or client are more likely to be culturally compatible (Kass et al, 1999; Marin, 1989). Although often providers do not accept patients who are on medical assistance or who are uninsured, racial and ethnic minority providers are more likely than non-Hispanic white providers to treat patients who are on Medicaid or are uninsured (HRSA, 1999). Thus, having more Latino providers in areas with higher concentration of Latino residents makes sense. However, there is a shortage of them. For example, in 1996 only 3% of nurses and 5% of physicians were Latinos (Gray & Puente, 1996). This is very low, as Hispanics represent 13% of the U.S. population. Unfortunately, the President's Initiative on Race reports the proportion of minorities that enroll in health related professions is decreasing (HRSA, 1999). This trend will have negative implications in health care for minorities.

**Table 5**

**Percentage of enrollment of selected minorities in health related professions,  
1996-1997**

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|                      | Hispanic | African American |
|----------------------|----------|------------------|
| Allopathic medicine  | 3.4      | 8.0              |
| Osteopathic medicine | 3.8      | 4.1              |
| Podiatry             | 3.4      | 3.7              |
| Dentistry            | 4.0      | 5.4              |
| Optometry            | 3.9      | 2.4              |
| Pharmacy             | 2.8      | 7.7              |
| Public health        | 8.8      | 8.0              |
| Nursing              | 3.9      | 9.9              |

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Source: HRSA, 1998.

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## ***F. Hispanics in southwestern Pennsylvania***

### 1. Demographics

Hispanics have been traditionally concentrated in the East and West Coasts, in the Southwest, in Illinois and in Washington, DC. In the counties that have been defined here as SWPA, Allegheny, Beaver, Butler, Fayette, Greene, Washington, and Westmoreland, the proportion of Hispanics has traditionally been very low. According to the 1990 Census, there were 12,099 people of Hispanic origin in SWPA. Most resided in Allegheny County, with 7,749 of them there (U.S. Census Bureau, 1998). Latinos represented around 0.5% of the total population of the region. At that time, the age structure was not different from that of Hispanics in the U.S. in general. However, unlike with national data, Hispanic females in SWPA outnumbered males. Educational level was higher than that of Hispanics nationwide. In SWPA, 79% had finished high school, compared to only 50% in the U.S. There were also fewer Spanish-speaking people that were linguistically isolated. In spite of this, the median income was between \$15,000 and \$24,999, similar to that of Hispanics at the national level (U.S. Census Bureau, 1998).

During 1998, I held informal conversations with members of the local Hispanic community and with several American and Latino health providers. It was their impression that the Hispanic community was increasing in numbers and that the increase was mainly due to immigration of blue-collar workers, mostly from Mexico. There are more quantitative indications of the rapid increase of this population group. As shown in Graph 1, in Allegheny County alone, births to Hispanic mothers increased by a factor of 1.75 between 1989 and 1998, from 82 to 145 (Allegheny County Health Department (ACHD), 2000). More than two-thirds of the 1997 and 1998 births were to a Mexican mother. Unless a sudden and dramatic change in fertility patterns has occurred, this increase in births also reflects an increase in the population of Hispanic mothers and confirms the “impression” gathered before.

At the time this study was started, there were no known estimates of the current size of the Hispanic population by county or any smaller civil subdivision. Other techniques to estimate population size were not feasible. For

example, capture-recapture techniques needed at least two relatively good lists of the population. The largest lists available had 500 names or less. In addition, they were limited to Allegheny, had many foreign elements, and/or were biased to a particular subgroup of the population (i.e., scholars, students or professionals). A different technique takes into account the density of elements in a particular area. However, no updated list of Hispanics by blocks or census tracts was available, and measuring density was not feasible (Kalton, 1991; Scheaffer et al, 1996; Sudman et al, 1988).

**Table 6**

**Latino population of southwestern Pennsylvania and the United States. Selected data, 1990**

|   | Southwestern Pennsylvania |            | United States |            |
|---|---------------------------|------------|---------------|------------|
|   | Number                    | Percentage | Number        | Percentage |
| Total population                              | 12,099                    | 0.50       | 21,900,089    | 8.81       |
| Age group                                     |                           |            |               |            |
| < 15  | 2,095                     | 24.01      | 3,507,371     | 39.65      |
| 15-64   | 8,365                     | 69.14      | 14,351,122    | 65.53      |
| 65+   | 829                       | 6.85       | 1,056,196     | 4.82       |
| People who speak Spanish at home <sup>a</sup> | 17,586                    | 0.77       | 17,345,064    | 7.52       |
| Linguistically isolated                       | 1,108                     | 6.61       | 4,615,035     | 26.61      |
| Finished high school <sup>b</sup>             | 5,647                     | 79.04      | 5,592,573     | 49.81      |
| Median income                                 | 15,000-24,999             |            | 15,000-24,999 |            |
| People under poverty                          | 2,263                     | 19.58      | 5,403,492     | 24.67      |

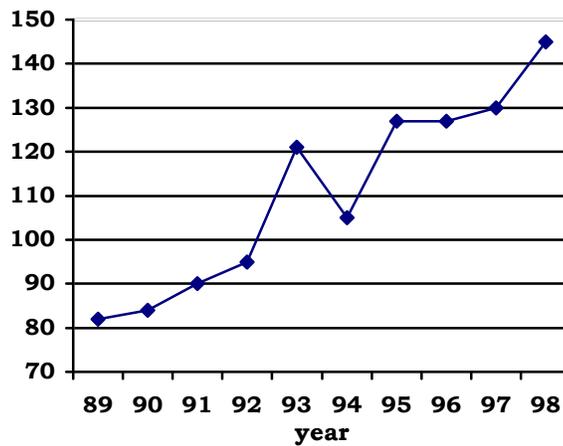
Source: U.S. Census Bureau 1998.

<sup>a</sup>Denominator are all people 5 years and older

<sup>b</sup>Denominator are all people 25 years and older.

Information from birth certificates provided the only objective population data regularly collected about Hispanics: the number of births to Hispanic mothers (ACHD, 2000). If the Hispanic community had increased by a similar

factor to the births (1.75), there should be approximately 12,000 Hispanics in Allegheny County in 1998-1999 and about 19,000 in SWPA. Regarding the population aged 18 and older, there were 8,577 Hispanic people in the seven counties defined as SWPA in 1990. The expected number for 1997 would be around 13,500. This method of calculating the population is very rough, and there are many problems with it. For example, the actual number of Hispanics could be lower, because newcomers are believed to have a lower socioeconomic status and hence, might have higher fertility; fewer people may account for more births. On the other hand, the actual number could be higher, because most newcomers are believed to be male, and therefore, a greater increase in the number of adults would be needed to yield the same increase in the number of births. In addition, some people may not tell health providers they are Hispanic or Latino. To summarize, this estimation is inaccurate and there were many unknown variables. However, it was the best one, given the available data, and were the ones using for all data collection purposes.



**Figure 2**  
**Number of children born to Hispanic mothers in Allegheny County 1989 – 1998**

Source: Allegheny County Health Department, 2000

Later in 2000, the Census Bureau released county level population estimates by ethnicity. The number estimated by the Census Bureau in 2000 was 19,997 Latinos of all ages in the seven SWPA counties, and 13,007 Latinos 20 years of age or older in the same area. These data are still only estimates based on Census 1990 data. In March 2001, the first results of Census 2000 (U.S. Census Bureau, 2001) showed that the Latino population in SWPA was 17,457 and 11,937 of them were 18 years of age or older. The fact that the number estimated to design this study was not extremely different from the actual count is reassuring.

## 2. Health and health care

Little is known at the local level about the health status of the Latino population. There are several reasons, including that: it is a small population, and most agencies do not distinguish their clients by ethnicity. Some agencies do ask people to self-identify as White, Black, Hispanic, and Other; they may be more than one of these. When data collection does not distinguish between race and ethnicity, the data collected are inaccurate. For mortality, only Allegheny County Health Department has some data. There were 188 Latino deaths between the years of 1989 and 1997; the main causes of death were heart disease (35%) and cancer (25%) (ACHD, 1999). Data on access to health services by Latinos in Allegheny are also lacking. At this time, there are no special programs to cover Latino health care broadly in SWPA. However, a relatively new program in Pittsburgh, *Programa para la Familia Latina* (Program for the Latino Family), was started in 1999 thanks to the work of a Latina, Gilda Holly. It is administered by Family Resources, a non-profit organization whose primary goal is to prevent child abuse. Some insurance companies and some hospitals offer translation services for people that do not speak the language (Wilson, 1998).

In SWPA, a growing number of Hispanics face a health care system that is not specifically prepared to meet their needs. Therefore, this area is ideal for studying the various barriers to access to health care that Hispanics may encounter across the United States. If access to health care were equitable for Latinos in SWPA, then its main determinants would be the ones that indicate need, such as age and health status, not social, cultural, and/or economic characteristics.

## **G. Summary**

Access is defined as “those dimensions that describe the entry of a population group to the health care delivery system” (Aday, 1984, p. 13). The ultimate goal of access is to maintain or improve health status. However, determining how much health care access affects health status is not easy. For this reason, other measures are used. Equity, according to social justice, means that all have access to health care, and utilization is determined by need. Access is not equitable in the U.S., as the poor and minorities have decreased access to health care, when access is measured as having health insurance, having a regular source of care, and having visits to medical and dental providers. The characteristics of health care access for Latinos in SWPA are not known.

In 2000, there were 35 million Latinos in the U.S., and they constituted the fastest growing minority group in the nation. Latinos in the U.S., as a group, are young and socioeconomically disadvantaged, although diversity exists between subgroups. There is no single definition of the group itself that is unanimously accepted. For the purpose of this dissertation, the Office of Management and Budget (OMB) definition will be used. According to OMB (2001) Latino is “a person of Cuban, Mexican, Puerto Rican, South or Central American, or other Spanish culture or origin, regardless of race”. The U.S. Census Bureau (1999) uses self-identification to determine whether or not a person is Hispanic.

Most Latinos share a common colonial history and a common language. However, there are also many differences including country of origin, social class and reasons for immigration. Several cultural traits have been identified as characteristic of Latinos. These appear to be the importance of the concepts of family, respect, personal relationships, and community. Latinos in the U.S. tend to come together based on some common interests or tastes. This brings about an array of conflicts and the emergence of new identities. As an ethnic group, Latinos in the U.S. are still in a process of formation.

Although mortality rates for Latinos are comparable with those of the non-Hispanic White population, there are several areas of heightened concern,

such as accidents, diabetes, liver disease, homicide, infectious diseases, and oral health. Additionally, Latinos frequently confront the stress of immigration, putting them at risk of social isolation and depression.

Latinos are the ethnic group with the worst health care access indicators for children and adults. They have the largest proportion of uninsured individuals, of individuals without a source of care, and of people that reported barriers to access to the health system. Latinos are also the ethnic group with the lowest proportion of individuals with a visit to the doctor or the dentist in the past year. The determinants of health care access for Hispanics appear to be mainly socioeconomic. Although there are indications of cultural differences in concepts and understanding of disease and health care, these differences have not been widely studied.

The Latino population in SWPA has traditionally had many years of formal schooling, when compared to the Latino population of the U.S. in general. Income, however, has been low in relation to educational level. The last years have seen an influx of immigrants with fewer years of formal schooling, who come to work in service jobs, changing the demographic makeup of the local Latino population. There were over 17,000 Latinos in SWPA in 2000, mostly residing in Allegheny County. Data on the health of Latinos in SWPA are scarce, and data on their health care access are almost non-existent.

### **III. Methodology**

#### ***A. Overview***

##### 1. General description

This research focused on the influence of financial, language and cultural factors on potential and realized access to health care of Latinos in southwestern Pennsylvania (SWPA). For the purpose of this study, SWPA was defined as the counties of Allegheny, Beaver, Butler, Fayette, Greene, Washington, and Westmoreland. A sampling frame of Hispanics in SWPA was developed through participant observation. A face-to-face, structured, bilingual survey was conducted on a sample of 206 Hispanic adults. Analysis of survey data included construction of estimates and logistic regression. The hypothesized relationships among dependent, independent and control variables are presented in Figure 1. If access is equitable, characteristics that define need, such as age and health status, should have a significant effect on health utilization. The effect of social structure variables, such as income and acculturation should be insignificant. On the other hand, if access is not equitable, the independent variables, which relate to the social structure, should be significant after taking into account the characteristics that define need. Given the available evidence, it was hypothesized that access was not equitable. Additionally, access to health care for Hispanic children 2 to 5 years of age was described. However, no statistical analysis was conducted on the children's data, due to their low numbers.

The characteristics of language and cultural barriers to health care, as experienced by Latino individuals in SWPA, were explored in detail. Cultural dimensions of access are complex and not easily quantified. To understand the

manner in which they operate, qualitative techniques are necessary. Qualitative data were gathered by participant observation. The themes explored related to factors that affect the process of obtaining health care, the outcome of that care, and the solutions Latinos in SWPA apply when they face those barriers. Special emphasis was put on cultural and language factors. The results shed light on how culture and income affect health care access and why, providing a complement to quantitative data. It should be emphasized that it was not the purpose of this research to identify certain cultural characteristics, access problems or solutions as exclusive of Hispanics. Similar problems and/or solutions may or may not be shared by other groups, whose study is beyond the objectives of this research.

To interpret the findings in the context of a complex community structure, a comprehensive description of the Latino community in SWPA was developed. Qualitative data gathered during participant observation was the primary resource used, but a few results of the survey were also considered. The features of the community that have implications for health and health care access were emphasized.

## 2. Data collection methods

This research used a combination of qualitative and quantitative techniques. Qualitative and quantitative data complemented each other in presenting a better picture of health care access of Latinos in SWPA (Table 7). Becerra and Zambrana (1985) have advocated the use of survey research and ethnographic techniques, especially participant observation, in research with Latinos. They argue that while survey research may provide standard answers for a known number of participants, in many instances it does not allow explaining the results. Ethnographic techniques complement survey research as they allow “the data to speak,” helping clarify puzzling results, providing a way to verify survey findings, and providing illustrative examples. An example of a successful use of a combination of techniques is the study on models of breast and cervical cancer risk factors among Mexican American, Anglo women, and physicians, by Chavez et al (1995). Freidenberg et al (1993) used ethnographic and survey research to study health seeking behavior among Latinos in East Harlem. They

give an example in which both techniques are used in a process of mutual feedback. This approach increases the probability that survey results are more grounded than if they were not used together with ethnographic methods.

*a. Participant observation*

Participant observation was carried out from the beginning to the end of the data collection period, from October 1998 to February 2000. Identified goals were: 1) Develop a sampling frame of the Latino community in SWPA. 2) Obtain a comprehensive description of the Hispanic community in SWPA, its social, family and religious structure, and its culture in general. These data could not be obtained using quantitative techniques. 3) Select appropriate themes to be included in the structured survey, and select or create the questions for the survey instrument. 4) Build a relationship with members of the Hispanic community that could lead to trust and cooperation. 5) Explore in more detail the health and health care related experiences and expectations of Latinos in SWPA, from their own point of view.

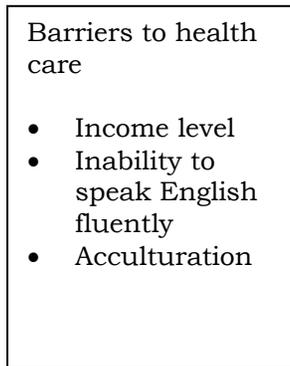
*b. Structured survey*

The instrument provided information about 1) demographics, 2) health needs, 3) potential health care access (i.e., having a regular source of care), 4) realized health care access (i.e., having a doctor visit in the past year), 5) income, 6) English proficiency and acculturation and 7) use of traditional healers. Questions about children's access to health care were asked to adults responsible for a child between 2 and 5 years of age. Additionally, performing survey interviews provided a "legitimate" reason to visit people's houses and conduct participant observation.

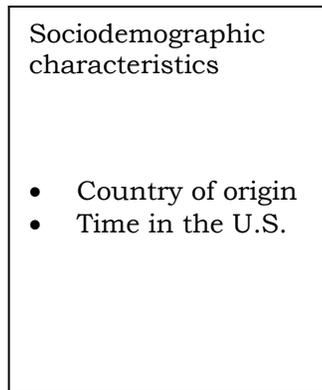
**Table 7****Data collection techniques, purposes and timeframe**

| <b>Technique</b>        | <b>Purpose</b>  | <b>Study phase</b> |
|-------------------------|---|--------------------|
| Participant observation | a. Develop a sampling frame of Hispanics in SWPA.   | Beginning          |
|                         | b. Inform questionnaire development for the structured survey.                                | Beginning          |
|                         | c. Develop a comprehensive description of the Hispanic community in SWPA.                     | All                |
|                         | d. Build trust and cooperation with the Hispanic community of SWPA.                           | All                |
|                         | e. Explore in detail the experience and expectations of Latinos regarding health care.        | Middle and final   |
| Structured survey       | a. Obtain quantitative data of Hispanic individuals and a child in their care.                | Middle             |
|                         | b. Provide a legitimate reason to enter people's homes and carry out participant observation. | Middle             |

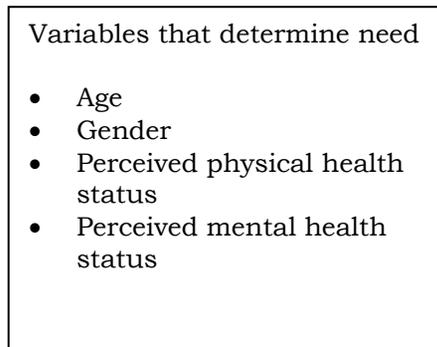
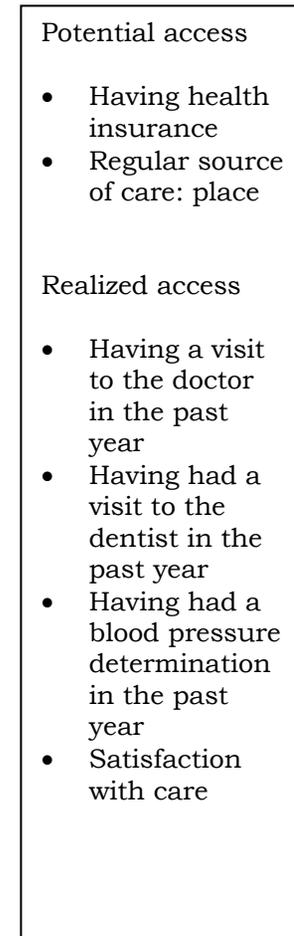
**Independent variables**



**Control variables**



**Dependent variables**



**Figure 3**

**Hypothesized relationship among variables considered in the survey**



## ***B. Participant observation***

### 1. Why participant observation?

Participant observation was used to relate to the different subgroups in the Hispanic community of SWPA, to build trust, to inform questionnaire development, to obtain data on the social, cultural, religious and family characteristics of Latinos in SWPA, and to explore health beliefs and practices. Participant observation is an ideal method when the goal is to describe and explain the phenomena under study (Hammersley & Atkinson, 1995). According to several authors, it can be instrumental in obtaining data on the subjects' own perception of their situation, providing a richness of detail that is missing in quantitative studies and tending to uncover issues that might have been overlooked or ignored by the investigator (Fabrega, 1990; Freidenberg & Hammer, 1998; Hammersley & Atkinson, 1995; Sherraden & Barrera, 1995). Freidenberg et al (1993) explain how participant observation has been useful to locate samples, especially when individuals may not be accessible through other means. Additionally, the participant observation approach has the advantage of raising community awareness of the study, which in turn has the potential to foster cooperation from the community, as described by Becerra and Zambrana (1985), Hammersley and Atkinson (1995), and Sherraden and Barrera (1995). In this way, carrying out initial data collection made it easier to continue collecting data, and also opened new contacts to reach a broader group within the community.

### 2. The questions addressed

Ethnographic research is designed to change as the study progresses. Hammersley and Atkinson (1995 p. 24) say that it usually starts with a few research questions, or “overshadowed problems.” As a result of initial research, new lines of inquiry, unknown prior to the start of the study, develop. One of the values of participant observation is the ability to uncover new “questions.” Some of these questions may be pertinent to the central theme of research and may be pursued next. This cycle repeats itself, refining the questions even as some are answered (Hammersley & Atkinson, 1995).

During this research, the questions explored by participant observation changed over time, not only because new issues emerged during the observations themselves, but also because the object of conducting participant observation changed, by design, as the research progressed. Initially, the goals were to construct a sampling frame, to build trust and to inform questionnaire development. The main questions were, Where can Latinos in SWPA be found? How? Is there a *barrio*? What is the best way to approach Hispanics so that they accept to participate in the study? What are the issues that are important to explore regarding health care access? What demographic variables should we consider?

Data regarding community makeup and health beliefs were gathered and recorded, but were not the main focus of participant observation at this initial stage. As time passed, the main goals were to develop a comprehensive description of the Latino community in SWPA and to discuss health care access as perceived by the community. In both cases, exploring one question usually led to a new question, and issues that had not been foreseen emerged. An example of this was the importance of informal arrangements to obtain health care. Some of the questions raised were partially answered, and some could not be answered by this research, such as one question about the role of fatalism in health care seeking.

When attempting to describe the community, a set of questions arose, such as, Do Latinos in SWPA constitute a community? Or are they part of several communities? Why? What are the features of this group that make them a community? What are the obstacles to this group becoming a community? To respond to this set of questions, several smaller questions came into play, such as, Who is Latino? Where did they come from? Why? How? Did they come to stay? Are they planning to stay? Do they speak English? Where do they live? Where do they work? How much do they earn? Where do they meet? Why do they meet? What is the importance of food and music in defining identity? What do the concepts of ethnicity, race and class mean for Latinos in SWPA? What word do they prefer to use to define themselves? Who is a *mestizo*? Do Latinos share similar “cultural traits”? How do Latinos define their ethnic identity (or assert it)?

Health related issues included health beliefs, concepts and practices, such as, What kind of health beliefs do Latinos hold? Who is considered sick? How does a person get sick? Is there a belief in *curanderos* or other traditional healers? What is the importance of prevention? How much pain is acceptable? When is it appropriate to seek care? What is the best way to seek care? Why? Is health care in the U.S. seen as too complicated, bureaucratic, or impersonal? Are paternalistic attitudes expected from doctors and health personnel - by whom? Is fatalism a deterrent to seek health care or to act in a preventive manner? Is language a problem for people who face the health system in the U.S.? When (when sick or all the time)? How do cultural traits of Hispanics affect their view of the U.S. health care system and their use of it? How does personal space affect the provider/patient relationship? What role does family involvement play in health care and health care seeking? What are the strategies used to work around cultural barriers to care? How do people work around their financial barrier to care? How do they make “informal arrangements”? Who chooses informal arrangements? Why do people choose informal arrangements? Are the informal arrangements Latinos make reliable? Why or why not? What are the risks and benefits of such arrangements? Why are they culturally acceptable? What are the implications of the existence of a community for health? For health care access?

### 3. Sampling occasions and subjects

Participant observation was carried out during 17 months, from October 1998 to February 2000. Relationships with different organizations and people in the Latino community helped identify places and occasions in which Hispanic people might be found. They also provided contacts that, in turn, identified more potential interviewees. The sample of people and occasions where participant observation was carried out was not random. However, even though no mathematical selection was done, efforts were made to achieve a sample that represented the range of variation within the Latino community, as the literature recommends (Chavez et al, 1992; Freidenberg & Hammer, 1998; Hammersley & Atkinson, 1995; Weiss, 1994). Weiss suggests that one look to places and events that can represent subjects with contrasting characteristics.

Some should have contrasting independent variables; for example, those who are poor and those who are more affluent. Others should show contrast in dependent variables, for example, those with and without health insurance. Yet others should show contrast in context, such as rural and urban dwellers, or in dynamics, such as those with families in the area, and those who are alone.

Because of my position in the community and in the University of Pittsburgh, my acquaintances were biased toward middle-aged and college-educated people. Therefore, special effort was directed at obtaining contacts representing other types, such as individuals with few years of formal schooling, individuals who worked in agriculture or the service sector, the elderly and young adults. Once contacted, visits were arranged to spend as much time as possible with representatives of those groups. Attending regularly the only weekly Catholic mass in Spanish in the area made it easier for me to contact other Catholics. Therefore, efforts were also directed toward contacting people who belonged to other religious groups. These efforts had mixed results.

Regarding occasions, the most easily available for me to observe were the public or semi-public ones, such as festivals or church gatherings. Therefore, I tried to visit with people during “regular days” as much as possible. Connections established early in the research and through survey administration were instrumental in achieving this goal.

There were limitations to the sampling described above. One was the limited number of contacts made. There must be people who I could not reach or contact. They might differ substantially from those I was able to reach. Another limitation was time. It was impossible to observe every occasion and relate to every person. However, as Weiss (1994) explains, any list built by reaching contacts tends to underrepresent those more isolated. I tried to diminish these limitations by increasing the range, as described in the previous paragraph, but it is most likely that they were still important.

Commonly, especially in the beginning, people who were knowledgeable regarding the community advised me on how to proceed and who to contact. This was more noticeable when the contacts were educated people, who enjoyed discussing research methods. Other gatekeepers thought they had to tell me whom I should contact. As Hammersley and Atkins (1995) and Weiss (1994)

point out, it is not rare for participants to try to influence the researcher. They can be genuinely trying to help or, consciously or unconsciously, may be trying to influence the researcher in a certain direction. For example, some conservative upper class professionals thought that it was necessary for me to talk to other professionals and downplayed the importance of gathering data from lower class immigrants. No matter what the source, all such attempts can be treated as data. It was informative to know whom some people thought I should contact and whom they thought I should not. This approach avoided arguing with subjects and allowed the maintenance of a reasonably good rapport with them, no matter how much we disagreed.

During all of the 17 months of participant observation, I attended events of the Latino community that took place in public places, such as picnics, church services, religious and lay festivities, and public festivals. I also attended many social gatherings at homes and restaurants and visited many people in their homes. I talked on the phone with many individuals I contacted and those who contacted me. To participate in the setting, I engaged in small talk, danced, answered some questions about myself, accepted food, visited sick people at the hospital, and helped with minor household tasks. All these activities have been described as appropriate when doing participant observation and qualitative research (Becerra & Zambrana, 1985; Ludwig-Beymer et al, 1996; Marin & VanOss Marin, 1991; Sherraden & Barrera, 1995).

Krauss et al (1997) say that class, race, and education frequently separate researchers from subjects. To counteract this problem, they recommend establishing some common ground. In this case, I too was separated from many members of the Latinos community by one or more of the factors listed. The most useful themes of conversation for establishing a common ground with community members were (ethnic) food, raising children and being an immigrant. Drawing from personal experience to find commonalities enhances communication with research subjects, as described by Hammersley and Atkinson (1995) and Krauss et al (1997). Being a mother and being bilingual are traits that have been used by Chavira-Prado (1992) in ethnographic research to establish a common ground with Latino subjects. In New York, Krauss et al (1997) used motherhood as a common ground to

establish rapport with subjects. The setting of the events was generally informal, and people usually talked comfortably.

It is recommended to be as open about research as possible with the people studied (Hammersley & Atkinson, 1995). I frequently reminded the Latinos in the different settings that I was doing research, so that they knew they were being “observed.” This was necessary, especially when I felt that people in the setting started regarding my presence as “normal” and my asking questions as part of the social conversation. By reminding them of my research, I allowed them the opportunity to avoid saying something they did not want me to record. It was important to me to be honest about what I was doing and avoid deceiving people, especially when issues as thorny as immigration might have been discussed.

As time passed, it became clear that some people wanted to voice their concerns and opinions about health and health care in the United States. This provided me with the opportunity to explore more deeply some attitudes and beliefs of Latinos in SWPA about these issues. Several people in the community knew about my research and some felt they possessed relevant information I should know. Several individuals I was acquainted with, and a few I had not met before contacted me via phone or in person to narrate to me a personal experience with health care or the experience of a person they knew. Other people identified me with health care and called me to ask for referrals, to find out how to get health insurance or free care, or to help them deal with the health system. This was an opportunity to learn firsthand about the problems people faced and how they dealt with them. I listened to them, visited some of them and helped those who needed simple things, such as translation of a form. I was able to refer most of those seeking care to a social worker in a program for Latino families. Some people contacted me because they wanted to be included in the survey. They did not understand why I would decline their offer to participate. It was not easy to explain what random sampling was and why it was necessary. A solution was to let them know I regarded their experiences with health care as very important and to encourage them to tell me about those experiences.

Frequently, participant observation took the form of time spent in the home or office of interviewees after the close-ended survey was completed. Often they wanted to talk more about health or about other issues. They also wanted to know more about me, the survey and its uses. Most interviewees offered food and/or something to drink, especially coffee. I accepted those offers and welcomed the opportunity to spend more informal time with them. Frequently, other family members, children and adults, or even friends, joined in. In some cases, it was appropriate to attend the interview session with my family. In those cases, typically, a very short social conversation preceded the interview. Then, the interviewee and I were shown to a more “private” area, such as the kitchen, where we completed the survey. After that, more conversation and often a meal followed. The survey would not have been possible without the contacts I built through participant observation. However, a great deal of participant observation was facilitated by the survey, which gave me a legitimate reason to visit people’s homes and workplaces.

It was important to follow the participant’s rules for each meeting, as possible. This not only showed respect, but also provided insights into cultural norms and values. Some of these norms were easy to understand and follow, as they were not very different from my own, but some were different and I had to adapt. It was important to go to the meeting open-minded and be able to adapt quickly, since it was difficult to know beforehand what the meeting would be like. For example, at one visit for a survey interview, it was “obvious” for the interviewee that we were to have dinner at his home. It was also obvious for him that my children were to be there. My husband had to leave to pick them up. What I thought was to be a 60 to 90 minutes session took five hours.

No individual was compensated financially for his or her participation. On the contrary, they usually provided food, coffee and little presents to me. Frequently people thanked me for doing the survey interview. I reiterated that it was I who had to thank them for their help. In some cases, there was an opportunity for me to return a favor, which was viewed as a “normal” part of a reciprocal relationship. For example, an interviewee who did not speak English called me a week after the interview and asked me to help him fill out some papers for his insurance. In some instances it was appropriate to give

something to the contact person. For example, when visiting for the second time some people who work in agriculture, I took a homemade cake. When I left, they gave me a box full of peaches. On a different occasion, a lady asked that I please dig some dandelion roots she needed for her home remedies and bring them with me the day of the survey interview. The next morning, she offered me a homemade breakfast. I never gave money to the participants. I felt that giving money would have been insulting, though I have no real data to back up this assertion.

#### 4. Sampling frame development

During the phase of sampling frame development, short summaries of the proposal were distributed to leaders of groups of potential respondents. Individuals, groups, and organizations provided basic information about their clients, affiliates or friends. The use of participant observation to develop a sampling frame of Hispanics has been described by Becerra and Zambrana (1985), especially when there is no way to develop a complete sampling frame from existing records. Since confidentiality was an issue, lists with names and addresses were not always available. In some cases, sex and national origin were provided; in other cases only e-mail addresses were available. Sometimes no characteristics were revealed, except for the number of people in the list. Each person had an identification number to be entered into the sampling frame. More details on the sampling frame can be found later in the section about the survey.

#### 5. My position in the community

I have been living in Pittsburgh for nine years, and I have developed many acquaintances and relationships with Latinos and non-Latinos. My views about the community, as the views of everybody, are not completely objective. I tend to develop an opinion about different issues that affect the Latino group in this area. It is not rare that I participate in community activities. For example, I was active during 1999-2000 in raising awareness about the need to respond to the Census 2000 questionnaire.

Many people contacted during the study knew I have been active in a local organization, the Latin American Cultural Union (LACU) for a few years. I was in charge of social events, such as the Christmas party and the annual picnic. This position made it easier for me to contact key people and to be identified as a community member, rather than an outside researcher. It also presented some difficulties. First, it required that I perform both roles well, the one of researcher and the one of social coordinator of LACU. This resulted in a tremendous amount of work. Second, it was difficult for community people and for me to separate both functions. Often people used time after the survey interview to voice their concerns or wishes about the activities of the LACU.

My social situation, and therefore the range of places I could attend, was fixed to some extent by my being a middle-aged Hispanic woman. This was even more so because I belong to this community. Being an outsider could allow the researcher more liberty to move around. At the same time, it would preclude her from obtaining certain data (Hammersley & Atkinson, 1995). To counter this limitation, it was important to build rapport with all sorts of people (Chavez et al, 1992). This included talking about things as different as raising children, *telenovelas*, statistics, seeing patients, being overwhelmed by winter weather, and typical food. This allowed me to contact and develop a common ground with people with few or many years of schooling. However, there were some things I could not do because of my social role. For example, I could not attend a soccer match of Mexican men who worked in restaurants, even when that could have led to broadening my contacts.

As a part of this community, I could not leave the field and I could not be an outsider, rather was a native. In many occasions, especially those that would have been part of my social life anyway, I had to make an extra effort to observe and to develop some marginality. This is usually the case when the researcher is part of the community under study, and it makes it even more important to be aware of personal positions and biases (Hammersley & Atkinson, 1995; Freidenberg et al, 1993). Because of these features, and because participant observation took place at any time of the day and during any day of the week (frequently all of them), it was the most enjoyable part of the data collection. At

the same time, it was the research activity that put the most stress on my personal life and that was most burdensome.

## 6. Data recording

Field notes were recorded at least once a week, or more frequently as needed, and stored electronically. However, it was difficult to do so daily, because of the need to contact new interviewees and do survey interviews themselves. When time was scarce, I jotted down notes to serve as reminders of the most important features of the observation. Full notes were typed later. Notes included the facts of the observation, my thoughts about it, and what I thought other people interpreted from the events. I also recorded events and news about Latinos in SWPA. The notes were kept locked at the University of Pittsburgh and none of the subjects had access to them. All quotes of subjects' words have been written as they were spoken, and subsequently translated into English by myself.

## **C. Survey**

### 1. Type of survey

An individual face-to-face survey of a sample of 206 Latinos in southwestern Pennsylvania was undertaken. If a face-to-face interview was not feasible, the interview was conducted over the telephone. Some studies have found that the response of Latinos to face-to-face surveys is higher than to telephone or mail surveys (Casas, 1992; Gonzalez et al, 1997; Ludwig-Beymer et al, 1996). However, recent data from the Western United States (Howard et al, 1983; Lorig et al, 1997) indicate that telephone surveys may have a comparable response rate and data quality. However, there are still other benefits of a face-to-face survey. This method ensures that literacy is not an issue (Aday, 1996; Palacios & Sheps, 1992) and calls for personal interaction, needed for participant observation. The main drawback of face-to-face surveys is that they take longer and therefore, may be more costly than telephone interviews. In this case, a list of telephone numbers of Latinos was not available. In addition, a telephone survey was not convenient. As Erickson

(1994) said, many of the newest members of the community, those most likely to have had health care access problems, might not have had a telephone number. Some might have had phone numbers that were frequently disconnected because of lack of payment (Sherraden & Barrera, 1995). Others might not have a listed number due to being a mobile population or because they might have requested their number to be unlisted, as Erickson (1994), and Marin and VanOss Marin (1991) say often happens with Latinos in other areas of the U.S.

## 2. Description of the sampling frame and its limitations

I was unable to find a list of Hispanics in SWPA that would constitute a reasonable sampling frame. Consultations were made with the University Center for Social and Urban Research at the University of Pittsburgh, with people who work privately with surveys in the area, and with Hispanic/Latino researchers. Using Hispanic surnames as a means of identification is not sensitive enough. Many Hispanics do not have Spanish surnames. They might have acquired a different surname by marriage, they might have a Native Mexican, Central, or South American surname, or they may have different origins, including any European or Asian country. To complicate matters further, many Spanish surnames are indistinguishable from Italian surnames (Fox, 1996; Howard et al, 1983). Random digit dialing was not feasible due to the small proportion of Hispanics in the area and the aforementioned problems with phone availability. There were no particular communities or neighborhoods in SWPA where Hispanics lived. Therefore, we could not do a cluster sample of households from an area where Latino people were concentrated, as is frequently done in other metropolitan areas (Aday et al, 1980; Ludwig-Beymer et al, 1996).

An alternative to using an existing list was to develop a sampling frame of the Hispanic population in SWPA. This was an attempt to obtain quality data on Hispanics when more traditional methods were of limited value, and addresses objective 22.03 of the Surveillance and Data Systems section of Healthy People 2000 (DHHS, 1998). This objective called for the development and dissemination of procedures for collecting comparable data for each of the

national health objectives and for the incorporation of them into the Public Health Service data collection system. This research was a first attempt to get at least some data on a population for which no local health data existed. This was accomplished through participant observation, as described above. Giachello (1996 a) explains that the monetary and time costs of constructing a sampling frame for a scattered population can be high. This, coupled with the low coverage that a telephone-based frame would have, made the chosen option the best one available, even though it was quite imperfect.

The resultant list was ordered by putting individuals from the same group or list together. For example, if 35 people were the contacts of Pastor García (a fictitious name), then they would be listed consecutively in the frame. If 15 people were the contacts of Jacinta, an instructor at a local college, then those 15 people would also be listed consecutively in the frame. In an attempt to obtain an ordered list, groups or lists were ordered by the occupation of one or more known members of the group. At the top were professionals and managers, followed by people in clerical work, groups comprised of “mixed” people, students, agricultural workers, and other laborers. In our example, if it was known that one of the members of Pastor García’s list worked as kitchen help, that list would have been listed after Jacinta’s list. Those groups considered “mixed” were those that had students, professionals and laborers, such as those who attended the Spanish-language Catholic mass. The purpose to develop an “ordered list” was to achieve some degree of implicit stratification, since intra-list variation was presumed to be lower than inter-list variation. Implicit stratification can be beneficial in systematic sampling because it increases the representativeness of the sample and decreases variation (Scheaffer et al, 1996).

Whenever names were available, duplicates were identified by the computer and deleted. A problem was that some names were similar but not equal (i.e., Roberto Pérez and Bobby Pérez). In such a case, the same person might be listed by a slightly different name or it could be a completely different person. Only names that were exactly the same were deleted.

The sampling frame developed had several limitations. Even when I tried to make it as complete as possible, it only included 16% of the adult population

of the area, estimated to be approximately 13,500 people. Even if frame construction would have been extended in time, it is unlikely that it would have ever reflected the Hispanic population of the area in its entirety. Some people may be more isolated and not related to community groups and organizations; others may simply refuse to participate or to give data on their acquaintances. The sampling frame remained “open” after interviewing began. This means that new lists were added as they became available. This is an unorthodox procedure and added complications to the statistical analysis of the data. However, it was necessary because the process of constructing such a sampling frame was time consuming. If no interviews were carried out within a reasonable amount of time, contact persons could have become suspicious of the legitimacy of the study. A clear cut sampling plan was weighted against the risk of reaching significantly fewer people, making the sample even less representative. The lack of completeness of the sampling frame constitutes the most serious threat to the validity of this research.

A second problem with the frame was that some people were listed more than once. For example, someone may belong to a church group and at the same time attend a school to study English as a second language. If the names of the people in the list were not known, they could not be deleted as duplicates, and some people were sampled twice. A third problem was the existence of foreign elements in the small lists that composed the frame. People who were not Latinos could not be deleted because the names of individuals in most lists were not known. Further, persons with a non-Spanish surname could not have been deleted for the reasons explained before.

### 3. The survey instrument

The survey instrument was available in both English and Spanish. Most questions were taken from the Hispanic Health and Nutrition Examination Survey (HHANES) (DHHS, 1985). Slight modifications were made to a few questions. Participants were screened using two questions: whether they were 18 or older and whether they were residents of SWPA (Marin, 1989). To identify Hispanics, some authors include only people who speak Spanish; others include only people with Spanish surnames. Both methods are inaccurate,

because a sizable number of self-identified Hispanics in the U.S. speak mainly English. Therefore, many researchers prefer self-identification as the way to identify Hispanics (Andersen, 1995; Diaz & Klevens, 1997; Fox, 1996; Marin, 1989; Marin & VanOss Marin, 1991; Stewart et al, 1999). The U.S. Census definition, based on self-identification was used. Since some people may not agree with the use of “Hispanic” or “Latino” to describe themselves, all those who identified themselves as Hispanic, Latino, Latin American, Chicano, Mexican, Cuban, Puerto Rican, Central American or South American, were considered Hispanic.

People who lived in households with children older than 2 but younger than 5 were asked questions regarding access to health services of one of the children in the household within that age group. It was expected that these children represented a random sample of all children 2 to 5 years of age under the care of those adults included in the sampling frame. Data on 25 children were recorded.

Questions that were originally only in English were translated into Spanish and back translated into English, to assure clarity and that the meaning was not changed in the translation. Later, two native Spanish speakers, not from my country, Peru, reviewed the translated questions. This was to make sure that the words used had a similar meaning for Spanish speakers of different origins. The Spanish-speaking reviewers suggested several changes in wording of the translated questions. Back translation and changes introduced by and discussed with other Spanish speakers different from the person writing the question are widely used to assure meaning is preserved, as described by Aday et al (1980), Alonso et al (1990), Badia and Alonso (1995), Burciaga Valdez (1993), Krongrad et al (1997), and Lorig et al (1997).

There are two issues when translating questions: one is language and the other is culture. Some concepts that are “normal” to people of the United States, may seem strange for Latin Americans. For example, “Of what country are you originally?” when translated culturally, should be, “In what country were you born?” “Americans” was translated as “Americans from the United States” because for Latin Americans, America is the name of one continent, from Alaska to Patagonia. This concept is shared among Latin Americans and is

explained by Latino authors, such as Gonzalez (2000), Stavans (1995) and Trueba (1999). The final English and Spanish versions of the questionnaire are presented in Appendix 1.

The consent form included an explanatory paragraph about the purpose of the study. It served to introduce the study and to assure confidentiality to the respondents. The consent form was also available in both English and Spanish. It is shown in Appendix 2. The protocol, survey instruments and consent forms were reviewed by the University of Pittsburgh Internal Review Board (IRB) and granted approval. IRB clearance is shown in Appendix 3.

Questions were sequentially numbered. Most questions had numerically pre-coded answers. This is, the number the interviewer circled was the same number that was to be entered for analysis. All close-ended questions had an option called “don't know” and another option called “no response”. Some questions had open-ended answers. All respondents were asked whether they would agree to participate in additional interviews or focus groups. Questions belonged to several groups:

*a. Demographics*

These questions were meant to capture essential data for independent variables that may affect potential and realized access to health care of the population surveyed. Questions addressed age, sex, education, occupation, marital status, country of origin, and time in the United States. Age was recorded as month and year of birth (Fang et al, 1997). Country or region of birth was preferred instead of ethnicity, because it may reflect better the differences among Latino groups, as proposed by Balcazar et al (1995). However, this is not comparable with most research on Latinos done in the U.S. Usually, the questions are similar to “What is your country of ancestry” or “To what Latino group do you belong?” A person born in the U.S. may identify himself as Mexican, for example. If the study were designed again, it would be necessary to include, additionally, questions about origin, not only place of birth. A question that was purposely not included was immigration status. Knowledge of such status could be useful in establishing better the nature of barriers to health care that Latinos experienced, but it had the potential to

scare respondents, as noted by Becerra and Zambrana (1985), Marin and VanOss Marin (1991), and Erickson (1994). Length of residence in the U.S. was recorded as a continuous variable. Education was characterized as “primary”, “high school”, “more than high school but less than college”, and “college or more”. It was assumed that the education question was easier to answer as a category than as a continuous variable, and that it posed less burden to the respondent (Halfon et al, 1997). Additionally, the number of years needed to complete a phase of education could vary among the countries where some of the interviewees were schooled.

#### *b. Financial status*

Financial status was represented by annual family income, measured as a categorical variable. It was recorded in brackets of \$10,000, with the lowest being “under \$10,000” and the highest being “\$50,000 or more.” Most studies, such as those of Hajat et al (2000) and Smith et al (1996), measure income as a categorical rather than a continuous variable. A few researchers, such as Halfon et al (1997), measure it as a percentage of the poverty level, but this requires more detailed information. It was thought that choosing from pre-established categories made it easier for the respondent to answer.

#### *c. Culture*

The scale selected was developed by Marin et al (1987) and validated with people of Mexican and Central American origin. This scale uses twelve questions that explore three dimensions of acculturation: language use, media preferences and social network. Its reliability has been estimated at 0.92. Another scale was used by Balcazar et al (1995) with Mexican-American women and by Moreno et al (1997) in Washington, D.C. That scale consists of five questions and is less burdensome to the respondent. During participant observation conducted while constructing the sampling frame, it was noted that some people had satellite TV and constantly viewed *Univisión* or another Spanish language network. Therefore, the longer scale was selected, because the shorter one did not include media preferences. An additional question that

was meant to explore cultural differences, but that was not part of the acculturation scale, asked about the use of folk healers in the past year.

*d. Language*

One item on language skills was included in the acculturation scale. It was used separately as a measure of English proficiency. Language barrier is the lack of ability to speak or read English fluently. Low English proficiency was defined as the self-evaluated ability to speak Spanish better than English or the ability to speak Spanish only. The limitations of this measurement is that it was affected by each respondent's subjectivity and also that many people were quite proficient in English, but they still spoke Spanish better.

*e. Health needs*

Health status was measured using the Short Form 12 (SF-12) scale (Ware & Kosisnski, 1995). This scale has twelve items that measure physical, social and mental health and has been extensively used. It is a shorter version of the SF-36, a 36-item scale. The SF-12 correlates highly (>90%) with the SF-36, and they can be used interchangeably.

*f. Potential access to health care*

Questions, originally from the NHIS, that addressed whether the person had health insurance (private, public or from armed forces) and a regular source of care (a place and a person) and of what type were included.

*g. Realized access to health care*

Questions from the NHIS related to having seen a doctor in the past year or having seen a dentist in the past year were included. The dentist question was included because it has been noted that dental care is typically not adequate among Hispanics (Davidson et al, 1996; Treviño et al, 1996) and has been found to be a concern of Hispanic communities elsewhere (Ludwig-Beymer et al, 1996; Palacios & Sheps, 1992). Realized access to preventive services was measured by asking if the subject had a blood pressure determination in the past year, for adults, and by asking about current vaccinations, for children. The last measure of realized access was satisfaction with health care received. A

question about satisfaction with health care in general followed nine questions that explored three dimensions of satisfaction: convenience, cost and cultural. Some of those questions were taken from Aday et al (1984).

#### 4. Pilot test

The survey was pilot tested in Allegheny County with ten individuals completed it. Pilot testers were not randomly selected. Rather, some of the lists that comprised the sampling frame were chosen, as recommended by Aday (1996) and Sherraden and Barrera (1995). These lists were supposed to be of different sizes and of different kinds (i.e., a list from an organization, another of a group of friends, etc.). One individual within each of those lists was selected. This was an opportunity to test the contact procedure in general, the contact procedure with some of the different “lists” that comprised the frame, the questionnaire itself, and the data entry form. Testing the whole data collection and data entry process is recommend by Aday (1996). Some of the subjects interviewed in the pilot test were sampled later. They were contacted again to complete those questions that changed after the pilot test.

Fifty percent of the subjects interviewed for the pilot were female; their age range was 25 to 58, and they had been in the U.S. from 2 to 33 years. There were subjects in all categories of income, from under \$10,000 to more than \$50,000 a year. They all had different ZIP codes and represented seven countries. These results were not random, but purposive. It was important to test the interview with subjects of different socioeconomic backgrounds and from different origins, since the meaning of the words used in the survey had to be understood by a broad and diverse group. The results of the pilot test are presented in Appendix 4.

Two of the lists tested were not operational. One large list was found to have changed substantially. At this point, arrangements to obtain the new list were made. In the other case, the list itself had disappeared when a staff member left the organization. After talking with new staff members, a new list was prepared.

The contact procedure was noted to be slow in cases where several “layers” of contacts were needed. Typically, a “contact person” was called or e-

mailed. This person asked the selected member of his or her group whether or not he or she would agree to be contacted for the study. Sometimes this required several phone calls.

There was only one refusal in the pilot test group; one woman told her contact person that she preferred to decline the interview. Even when all others accepted the interview, they were only moderately receptive if I introduced myself more or less like “I am a student at the University of Pittsburgh and I am doing my dissertation on health care access for Latinos in southwestern Pennsylvania. These data are important to know how our community fares regarding access to health services. Would you agree to participate in a 15 minute interview?” People were more eager to participate if I said something like, “I am a student at the University of Pittsburgh, and I am doing my dissertation on health care access for Latinos in southwestern Pennsylvania. I am really asking a favor of Latinos in this area. I need to complete 200 interviews. I wonder if you could help me by participating in a 15 minute interview?” Apparently, participants were more likely to agree to help somebody out (in this case, to help me) than to contribute to a worthwhile scientific cause. This was not surprising, as Sherraden and Barrera (1995) describe that Latinos may be more willing to participate if they realize they are being helpful. Therefore, this was the format of the request in all cases after the pilot.

The questionnaire itself changed in several ways. Typos were corrected, and minor changes in wording were made. The question about difficulties to obtain health care had to be reworded two times, since it was confusing to both the interviewees and myself. It was tested with changes to the last four subjects, and it was easier to use. Finally, a scale to measure health status was added after five pilot interviews.

Pilot data were entered using an ACCESS® database. The database was modified to accept only valid values as answers for each question. The pilot test was limited, but helpful, especially because not only the instrument was tested, but also the sampling frame, the contact mechanism, and the data entry form.

## 5. Sampling process

A systematic sampling approach was used to sample five replicates, each with a different random start. An unusual feature of the sampling scheme had to do with the unavailability of a reasonably complete sampling frame. The method of building a sampling frame through community relationships was slow. Data collection started when the frame had 1,297 individuals in it. As the interviewing process progressed, some of the sampled individuals mentioned they had several acquaintances or knew a group of Latinos. In one case, a person volunteered a list of over 300 names of people who were served by an agency. These names were added to the frame before the next replicate was sampled. The advantage was that more people, that would have been otherwise missed, could be reached through this approach. Before sampling the last replicate, the sampling frame had 1,960 individuals in it. In total, there were 2,246 individuals who were in the frame at some point.

The sampled person was contacted directly, when appropriate. If he or she belonged to a group that required using a contact person, that contact person was asked to approach the sampled individual in his or her group. If no list was available, a random number was selected and that number applied to the group as a whole. For example, in a church with a regular attendance of 90 people, a random number, such as “25” was selected. When the service was underway, I counted the people in attendance. The person counted as number 25 was sampled.

If a person was sampled twice, that person was deleted and replaced by the person next to him/her in the list. If a sampled person turned out to be not eligible (i.e., a foreign element), that person’s name was deleted and replaced by the person next to him/her in the list, a method explained by Krosnick (1999). In both cases, to determine whether the replacement person would be the one listed immediately before or the one listed immediately after the chosen person, a random list of 50 numbers, that could be digits “1” and “2,” was constructed. A “1” meant the person listed immediately before was chosen; a “2” meant that the person listed afterwards was chosen.

The target sample size was limited to 200, mainly due to budgetary reasons and geographical constraints. Using the program EGRET SIZ ® (1992-

1993), the power of the study was calculated. For sample size calculation purposes, the dependent variable used was insurance status, because there were more data available on it than on the other outcome variables. The independent variable used was income (\$20,000 or more and less than \$20,000). Seven control variables were considered, six of them with two categories, and one with six. From the literature cited, some relatively arbitrary numbers were used. It was considered that 51% of Hispanics with “low” income and 30% of Hispanics with “high” income were uninsured (HRSA, 1999). The odds of being uninsured if income was “low” were considered 2.5. For proportions in the population of people in the “high” income category, U.S. 1990 figures for SWPA were used. The program was run for “Logistic Regression for Cohorts or Cross-sectional Studies.” The case-fraction used was 30%, to be conservative. A detailed description of the variables used in the power calculations is provided in Appendix 5. At alpha level 0.05, if seven covariates or control variables were used, a sample of 219 would yield a power near 80%. The results are as follows:

**Table 8**  
**Power vs. sample size results with 7 confounders (Results from EGRET SIZ)**

|       | Sample size at alpha level |     |      |      |      |
|-------|----------------------------|-----|------|------|------|
| Power | 0.2                        | 0.1 | 0.05 | 0.02 | 0.01 |
| 80%   | 126                        | 173 | 219  | 281  | 326  |
| 85%   | 150                        | 201 | 251  | 316  | 365  |
| 90%   | 184                        | 239 | 294  | 364  | 416  |
| 95%   | 239                        | 302 | 363  | 441  | 498  |
| 99%   | 364                        | 441 | 513  | 605  | 671  |

To allow for non-responses, it was planned to sample 250 people; 50 in each replicate. Each of the five start numbers was determined by requesting a computer program to produce a random number between 1 and the total number of people present in the frame. When a person could not be contacted, I

tried to find the phone number or address using the phone book, tried an alternative spelling of the last name, tried calling the phone company, and finally, tried asking key community people. At this point, if no positive results were obtained, the individual was considered not found. If a person would not answer the phone, or would not respond to the message, that person was called at least five times during three weeks. If there was no response, the person was considered not found. All non-eligible subjects were replaced, as were those who were not found. In total, 434 listings were sampled, and 206 interviews were completed. Of the 250 listings originally sampled, 149 completed interviews. A summary of each replicate is presented in Table 9.

**Table 9**  
**Summary information for each replicate**

| <b>Replicate</b> | Subjects<br>in the<br>frame | Total<br>listings<br>sampled | Surveys<br>completed | Non-<br>eligible | Repeated | No<br>contact | Refused   |
|------------------|-----------------------------|------------------------------|----------------------|------------------|----------|---------------|-----------|
| 1                | 1297                        | 75                           | 40                   | 18               | 0        | 13            | 4         |
| 2                | 1330                        | 72                           | 39                   | 14               | 0        | 15            | 4         |
| 3                | 1370                        | 84                           | 43                   | 14               | 2        | 21            | 4         |
| 4                | 1750                        | 100                          | 44                   | 12               | 3        | 40            | 1         |
| 5                | 1960                        | 103                          | 40                   | 26               | 2        | 39            | 5         |
| <b>TOTAL</b>     | <b>2246*</b>                | <b>434</b>                   | <b>206</b>           | <b>84</b>        | <b>7</b> | <b>119</b>    | <b>18</b> |

\*Total is not a sum; it is the total number of people that were in the frame.

#### 6. The survey in the field

Two hundred and six interviews were completed in 9 months, between June 1999 and February 2000. There were a few problems when contacting interviewees. Several contacts, especially those with fewer years of formal schooling, had difficulty understanding the random sampling process. Even after several explanations, they did not understand it or did not see any need for such a complicated arrangement. As a result, many lists did not yield a truly

randomly selected subject. Rather, the contact person designated a respondent. It is reportedly not rare that subjects try to influence the course of research (Hammersley & Atkinson, 1995). Even when the process was not exactly random, the interview was performed, because not including those subjects would have meant losing some of the community members that are the most difficult to find for a research study. Six interviewees answered that another person in the same household had been interviewed. All the others lived in different households.

When contacting organizations, there were a few problems, too. In one case it was impossible to obtain a response from the clients of a not-for profit organization. Apparently, the information had to go through several people until it reached the sampled person. Even after the project was granted approval from their research department, I obtained an answer only for 2 of the 12 sampled individuals. One completed the interview; the other one refused to be interviewed.

In general, after a subject accepted to be interviewed, we made an appointment. I tried to accommodate the time schedule and location preferences of interviewees. This included many interviews during weekends and evenings. Directions were obtained through the Internet and/or from the interviewees themselves. Most interviews were conducted face-to-face (86.9%); only 27 were phone interviews. Phone interviews were conducted when several appointments had failed and the potential interviewee was getting tired or when geographical and climatic factors precluded traveling to the interviewee's hometown (i.e., snowstorms). The most frequent places to conduct the interview were the home of the interviewee (29.6%), their workplace (15.5%), and a restaurant or café (13.1%). Other places included churches, libraries, parties, my home or office, and public outdoor areas.

All subjects were asked whether they preferred the interview in Spanish or English. Most of them (87.4%) interviewed in Spanish. It was originally thought that this could be a measure of acculturation, but apparently it also measured other things. Some native English speakers preferred the survey in Spanish to practice their Spanish skills. Some Spanish speakers preferred it in English for the same reason. Several interviewees stated that the language of

the interview did not matter to them. In those cases, the survey was conducted in Spanish, because it was easier for me to pronounce it. In this survey, the question was about “preference.” In other surveys the word “preference” is used as a proxy for English proficiency, and only those who cannot answer in English get a survey in Spanish (Fulton et al, 1995; Kirkman-Liff & Mondragón, 1991; Polednak, 1996).

All interviewees read or were read a consent form in the same language of the interview. Some individuals signed clearly, some wrote their initials, and a few wrote “x’s”. A copy of the consent form was given to the interviewee if he or she requested it. Some interviewees read it carefully and passed it to family members to see if it was appropriate to proceed. Others wanted to sign the form without reading it; I had to recite the text of the form to them and repeatedly request that they please looked at the paper. The form was read to the interviewee before all phone interviews.

The interview lasted 15 to 20 minutes in most cases, but some lasted longer. Some individuals provided paragraph-type answers to close ended questions. The question was asked again, until a close-ended answer was chosen. In all cases, conversation was kept to a minimum until the interview was completed. However, if after that the interviewee wanted to talk more about topics they considered important, a longer conversation followed, as described in the section on participant observation. In most cases, only the interviewee and I were present, but in some cases, a family member stayed the whole time. Many interviewees wanted to see the survey as I read it, so I placed it so that was easiest for them to read. Question 2, “Are you at least 18 years of age?” worked as an icebreaker for almost all people over 25.

To avoid leading participants, questions were worded and asked in a neutral way, following the same printed script each time (Aday, 1996). However, there were some changes to the printed script that were used consistently with all participants. They eased the interview process. Before question 1, I said, “I have to ask all questions as printed.” When asking question 68, “How long do you plan to stay in the area where you are living now?” I added every time, “this means SWPA.” Frequently, a word in the Spanish version of question 11,

“*interfirió*” (interfered), was too complicated, and I repeated the question with “*le dificultó*” (was made difficult).

### 7. Response rate

The response rate was calculated following the procedure outlined by Aday (1996), as shown in Table 10. There were 91 non-eligible subjects. Most of them did not fulfill the screening criteria. Fifty-two were non-Latinos; 28 lived outside the area or had moved out of it; 3 were dead or too sick and institutionalized and one person was younger than 18 years of age. Most of the non-Latinos were Italians, Spanish teachers, or somehow culturally involved with a Latino group. Additionally, seven sampled people were duplicate listings. Eighteen people refused to be interviewed.

One hundred nineteen listings were not reached for several reasons: wrong phone number or address, address or phone number could not be found (n=73), and never answered the phone or never returned a message left on their answering machine (n=46). In these cases, it was unknown whether the subject was eligible or not. To estimate the number of ineligible listings among those with an unknown result, it was assumed that the proportion of ineligibles among them was similar to the proportion of ineligibles among those with a known result. Those with a known result were the completed interviews (206), the refusals (n=18) and the known ineligible (n=91). The proportion of ineligibles was 0.29. Applying this proportion, it was estimated that 34 of the unknown were ineligible, and 85 were non-interviews. The response rate, representing those among the eligible who completed the interview, was 66.67%.

**Table 10**  
**Calculation of the response rate of the survey**

|          |  |   |              |
|----------|--|---|--------------|
| <b>1</b> | <b>Original sample size</b>              |   | <b>344</b>   |
|          |  | <i>Less ineligible individuals</i>                        |              |
| <b>2</b> | <b>Known ineligible</b>                  |   | <b>91</b>    |
|          |  | Deceased, /too sick and institutionalized                 | 3            |
|          |  | Duplicate listings  | 7            |
|          |  | Doesn't fit screening criteria                            |              |
|          |  | Moved outside the area                                    | 28           |
|          |  | Not Latino  | 52           |
|          |  | Younger than 18 years                                     | 1            |
| <b>3</b> | <b>Unknown ineligible<br/>(estimate)</b> |   | <b>34</b>    |
|          |  | <i>equals</i>   |              |
| <b>4</b> | <b>Eligible</b>                          |   | <b>309</b>   |
|          |  | <i>less</i>   |              |
| <b>5</b> | <b>Non-interviews</b>                    |   | <b>103</b>   |
|          |  | Refusals  | 18           |
|          |  | Estimated non-interviews                                  | 85           |
|          |  | <i>equals</i>   |              |
| <b>6</b> | <b>Completed interviews</b>              |   | <b>206</b>   |
|          | <b>Response rate</b>                     | 100* No of completed interviews / No<br>of eligible units | <b>66.67</b> |

Response rate calculated according to Aday, 1996.

The literature mentions response rates for Latinos that range from 49% to almost 90%. Marin et al (1990) report that response rates to two telephone surveys among Latinos, calculated in the same way as the one in this study, were 88.4% and 88.6%. In a New Mexico telephone survey, Howard et al (1983) obtained a lower response rate for Hispanics than for Anglos. The response rate was only 60% for Hispanic males and 69% for females compared to 75% and 78% for Anglos, respectively. The latter study calculated response rates including all non-contacted persons as non-respondents, instead of estimating the number of non-eligible among them and subtracting it. In a rural California area, a household survey of children obtained a response rate of 91% (Smith et al, 1996). However, they first conducted an enumeration to identify eligible households, and thus, it appropriate to say that the refusal rate was 9%. In New York City, a school-based survey of adolescents of Latino and Caribbean descent obtained a response rate of 70% (Sonis, 1998). The author does not say if the non-eligible were included in the denominator, but it appears they were not. Not enough information is presented in the article to recalculate the response rate. In a face-to-face household survey in an Illinois community, 210 out of 252 people approached agreed to participate, for a response rate of 83% (Ludwig-Beymer et al, 1996). The number of ineligibles is not reported, making it impossible to recalculate a response rate using the same method used here. Palacios and Sheps (1992) surveyed a convenience sample from organizations serving Latinos in Vancouver; their response rate was low (49%) and they attributed it to fear of immigration authorities and concerns about privacy.

In this research, the 66.67% response rate appears relatively low. Perhaps this was caused by the inability to contact people that might have been eligible. As pointed out by Krosnick (1999), it is difficult for face to face surveys nowadays to reach even a 70% response rate. This is due mainly to the general reluctance of subjects to answer surveys. However, in this case, most of the non-responses were the result of problems with the sampling frame itself, which included non-Latinos, and problems with the accuracy of phone numbers and addresses. Many subjects could not be found in the phone book, because they had unlisted numbers, because they had moved away from the area, or perhaps because their names were misspelled. Often, close to a year elapsed between

initial contact and actual sampling. Many people had moved, and their phone numbers had changed. The high mobility of the population, which is to be expected when working with minorities and immigrants, was also an obstacle (Marin, 1989; Sherraden & Barrera 1995). Especially problematic were the cases when the phone number of a contact for a list of more people “disappeared.” One, or perhaps several, sampled individuals could not be reached. However, in some cases, people who had been lost to contact at one point resurfaced later.

To maximize the response rate, every effort was made to obtain the sponsorship of local community groups. Many researchers, such as Becerra and Zambrana (1985), Marin and VanOss Marin (1991), Sherraden and Barrera (1995), and Giachello (1996 a) have recommended this strategy. The survey was advertised within the Hispanic community ahead of time. Information was shared three to four months before actual interviewing began, since it has been reported that Hispanics appear to need longer lead time to feel comfortable answering questions (Palacios & Sheps, 1992). Marin and VanOss Marin (1991) identify other issues, such as how threatening a survey is perceived to be for members of the community, especially for those with low socioeconomic status. Palacios and Sheps (1992) found that even when they used a Spanish-speaking interviewer, only about half of the subjects approached agreed to participate because of immigration status and concerns with privacy. This survey was announced at the Latino mass and on a radio program (*La Revista Radial Latinoamericana*, transmitted on Mondays at 6 p.m. on 88.3 FM). Since Hispanic media were few and reached a limited audience, letters briefly explaining the study and asking for support were sent to all groups identified during the developing of the sampling frame, were pivotal (Becerra & Zambrana, 1985). Telephone or face-to-face conversations with these people reinforced the letters. Word of mouth is reportedly the most powerful advertising tool among Hispanics (Marin & VanOss Marin, 1991; Casas, 1992). Letters of support from Hispanic groups and organizations were obtained (i.e., the Latin American Cultural Union, the Center for Latin American Studies at the University of Pittsburgh, and the Catholic priest). Legitimization was extremely important, especially in a community that might be distrustful of strangers (Aday, 1996;

Ludwig-Beymer et al, 1996; Palacios & Sheps, 1992). Every effort was made to contact informal community leaders and gatekeepers. Since the community was so loosely organized, many people were not really related to any of the organized groups. It was noted that after the first interview with a member of a “list,” obtaining appointments with other members of the same list who had been also sampled was much easier.

Eighteen sampled subjects refused to participate. In two cases, the people were not directly asked about the interview, but their spouses decided to refuse on their behalf. All the other subjects said they did not want to participate, either through their contact person or to me directly. The refusal rate, calculated as the percentage of refusals among eligible people contacted, was 8.04%. This number is comparable to what has been obtained in other survey studies with Latinos: 3.1 and 4.4% (Marin et al, 1990), 5% (Lipton et al, 1996), and 12% (Díaz & Klevens, 1997).

## 8. Data management

### *a. Data collection*

Subjects’ names, addresses, phone numbers and/or e-mail addresses were kept in a separate “contact sheet,” for each replicate. Changes in phone numbers were recorded there, as were the date and results of all attempts to contact the individuals. Finally, the ID number of the interview, place and date were also recorded. Contact sheets were kept by myself and, after I finished using them, they were locked in a file cabinet. No other person handled the contact sheets.

### *b. Quality control*

Data were entered into a database using a Microsoft Access® entry form. This had the advantage of precluding entry of out-of-range data, by limiting the possible digits accepted. After data entry was complete, the data file was transferred to SPSS®. New variables (for example, age) were calculated; several variables were recoded. Variables and values were labeled. Frequencies and descriptive tables were run to further eliminate the possibility of out-of-range

data. If the frequencies appeared out of the ordinary, the hard copies of the survey were checked. Several mistakes in data entry were corrected.

Some typographic errors had led to errors in the data. While checking the frequencies it was found that the percentage of people with public insurance was much higher than expected. Hard copies of the surveys were reviewed and it was found that a batch of surveys that had been photocopied from the same original had errors in the enumeration of answers. Therefore, the data was wrong. All surveys that used that version of the questionnaire were reviewed and corrected. The error affected 3 questions. Additionally, at this time, the variable transformation process was streamlined.

Finally, 20 randomly selected records (9.7%) were re-entered by myself into a copy of the original Access database. Frequencies from the same records, as entered by the data entry person, were compared to those entered by myself. Frequencies were compared and checked for differences. All differences were checked against the surveys themselves. For 139 variables, there were 13 mistakes in the original data corresponding to the 20 re-entered files. The actual number of errors was divided by all the possible errors and multiplied by 100. There were errors in 0.47% of the entries. No further attempts at correcting the data were made.

$$\frac{100 * 13 \text{ errors}}{20 \text{ surveys} * 139 \text{ variables}} = 0.4676\% \text{ errors per survey per variable.}$$

### *c. Missing Values*

The proportion of records that had missing values in critical variables was low. There were seven records (3.39%) with missing data on family income, the key variable with the most missing information. There were two records with missing values in the variables used to compute age. These records were two of the seven ones with missing data for family income.

Hot deck imputation was used to impute missing values (Aday, 1996; Korn & Graubad, 1999). In one case, another person from the same household had been interviewed, and her answer for family income was imputed for the

one that had the missing data. In another case, year and month of birth of the subject were recorded, but later he requested that it be removed from the data. That information was not used and data were imputed as in the rest of the cases. For the other subjects, the adopted procedure was to select a “donor” among the other interviewees. Since the subjects entered the sampling frame usually as part of a “list” or “group,” the closest record in the sampling frame that belonged to the same “list” or “group” and had completed a survey was selected as the “donor.” Once a donor was identified, he or she “donated” data for all variables with missing data. This procedure assumes that individuals from the same list or groups are more similar to each other than to other people in the sample.

#### ***D. Analysis***

##### 1. Participant observation data

A comprehensive description of the Latino community of SWPA was developed. It allowed me to put into context quantitative and qualitative data on health care access. Participant observation leading to the development of such a description continued until the end of the data collection period. All names used in the text to refer to study subjects are fictitious. In cases where a person could be identified if two separate episodes were linked to him or her, that subject was given a different name for each episode cited in the text. Field notes were read several times. Common themes were identified early in the research. Data gathered in participant observation were classified as themes. Themes were divided into two major groups: community issue themes and health issue themes. Field notes were entered into the qualitative data analysis program, Ethnograph® and coded appropriately. The data in Ethnograph were queried using themes, and common occurrences were noted. One of the weaknesses of participant observation, and of ethnographic research in general, is that it is not easily generalized. Several things can be done to improve our ability to generalize. An integral part of analysis was triangulation. This means that data gathered in different phases of fieldwork, at different events, or from different participants, but that relate to the same phenomenon

were compared to verify their consistency and accuracy, as described by Hammersley and Atkinson (1995) and Weiss (1994). Triangulation helps to counter threats to validity. Data from one source may be biased or might have been misrepresented (intentionally or unintentionally). It is especially important if the same finding is obtained from two or more participants who were different among themselves, for example, one lower class and one upper class participant, or several participants from different countries. For example, it was important when a provider and some health care users told me about the same event or the same causes for a problem.

Interpretation of data required writing up the results and trying to make sense of them. The process of writing was a tool for analysis because it forced me to clarify concepts. Often, this included asking new questions, such as Why? Who? and How? In every case, alternative explanations have to be considered. Additionally, a review of the literature, especially of data from other Latino communities in the U.S., was used to shed light on the results obtained and to formulate new relevant questions.

To address research questions, indicators were developed using themes found in the literature. Then, the data were examined to find if the indicators were present in the population under study. For example, solidarity and ethnic identification could be two of several indicators of the existence of a community. However, some of these questions could not be answered by the data that had been gathered.

Ethnographic research has been criticized because some say it is not objective. Brink (1994) argues that respondent's narrative responses are more an attempt at self-justification than an accurate description of their experience and that the researcher's point of view may influence the way the data are interpreted. However, Bibeau (1997) contends that social scientists examine actions and practices, which "are made intelligible through the interpretation of actors themselves...These discourse of participants represent the point of view of the actors themselves and constitute basic information of the social scientists" (p. 253). Discourses have to be considered in their historical and social contexts to be interpreted. Regarding the influence of the researcher's subjectivity, we could argue that it is present in all types of research, as stated

by Becerra and Zambrana (1985) and McKinlay and Marceau (2000), but that biases are usually unnoticed. For this reason, it is important to disclose our own points of view. In my case, as explained in the conceptual framework, I am looking at the problem of health care access from the point of view of social justice, and I also have a vested interest in the development of the Latino community of SWPA of which I am a part.

## 2. Survey data

There were two sets of individuals, children and adults. They were considered separately for the analysis.

### *a. Children*

The size of the sample could not be determined beforehand, but it was much smaller than the adult sample, as expected. Only 25 subjects had a child between the ages of 2 and 5 in their care. If two children between 2 and 5 lived with the interviewee, the one with the latest birthday was chosen (Marin & VanOss Marin, 1991). Many other adult interviewees had children in their care that were younger than 2 years of age, or older than 5, but data on those children were not collected. The number of records was insufficient to perform statistical analysis. Descriptive statistics and cross tabulations were used for these data. Even when no hypothesis were tested, it was still important to obtain a basic description of access for children because Hispanics are a young population and children's health care access issues are presumed to be important. A descriptive summary of the results is shown in Appendix 6.

### *b. Adults*

Before analyzing the data, some variables were recoded and others were computed. A continuous variable for age, in years, was computed and re-grouped into two categories, "18 to 44 years" and "45 and older." Others have used three groups, 18-24, 25-44, and 45-64 (Zambrana, 1996 a). In this sample, there would be too few individuals in the first group, complicating the analysis. People from 21 countries were interviewed: Argentina, Bolivia, Brazil, Chile, Colombia, Costa Rica, Cuba, Dominican Republic, Ecuador, El Salvador,

Guatemala, Mexico, Nicaragua, Panama, Paraguay, Peru, Puerto Rico, Spain, United States, Uruguay, and Venezuela. To divide Latinos in regions of birth, often only the three first groups are used, as they are the larger ones in the U.S. (Treviño, 1985; Hajat et al, 2000). However, in SWPA, South Americans appear to be a large group. Their proportion of Cubans and Puerto Ricans was relatively low, when compared to other areas in the U.S. Country of birth was recoded into six categories: Mexican, Puerto Rican, Cuban, Central American, South American and Other. County of residence was dichotomized into “Allegheny” and “not Allegheny.” Education was dichotomized as “less than college” and “at least some college.” Time in the U.S. was dichotomized into “less than 5 years” and “5 years or more,” as done by Thamer et al (1997). Income was recoded into “less than \$20,000” and “\$20,000 or more.” The initial cut point of \$20,000 was used in several previous studies (de la Torre et al, 1999; Hajat et al, 2000). The acculturation index was calculated as the average of the twelve responses (Marin et al, 1987). An index of 1 to less than 3 was considered low acculturation; one of 3 to 5 was considered high acculturation. A similar breakpoint was used by Blackhall et al (1995) when applying Marin’s short scale with Mexican Americans. A person who stated that he or she was equally proficient in English and Spanish was considered to have high English proficiency. The physical and mental health status summary measures were computed as recommended by Ware and Kosisnski (1995). The median for the total U.S. population was used at the cut point between “good” and “bad” health status. The cutoff values were 53.55 and 52.85, for physical and mental health status summary measures respectively. The corresponding standard deviations were 9.45 and 9.59 (Ware and Kosisnski, 1995). The dependent variables were all dichotomous: insurance status, regular source of care, having a visit to the doctor in the past year, having a visit to the dentist in the past year, having a blood pressure determination in the past year, and being satisfied with care. It was decided not to use the variable “use of traditional healers,” since only 7 people in the sample indicated having used them.

*c. Sample results and weights*

The demographics of the sample and those of SWPA Latinos in the 1990 Census are shown in Table 11. For example, the proportion of people with lower education and lower income was smaller in the sample than in the 1990 Census. The proportion of people of Mexican origin and those with fewer years of formal schooling were also smaller in the sample than in the 1990 Census. Surprisingly, the proportion of males and females was very close to those obtained by Census 1990 (U.S. Census Bureau, 1998) for the same geographical area. Additionally, it was assumed that there were too few native English speakers in the sample, perhaps due to difficulty finding them as they did not tend to associate heavily with immigrants, did not “stand out,” or were loosely or not organized. The biases of the sample could influence results, because a population with more years of formal schooling would reflect on better income and/or larger proportion of insured people. More educated people might be more able to deal with the health care system. The regional groups were biased, giving a misrepresentation of the community's problems. Even when this was the best sample that could be obtained in the area, all the biases made it meaningless to compute estimates based on the original data.

To address the bias, weights were applied when computing estimates. Data on the weighting procedure can be found in Appendix 7. Following the method described by Korn and Graubad (1999), three types of weights were considered:

- 1) Design weights account for different probability of selection, given that the sampling frame had different numbers of elements for each replicate. They were computed for each replicate as the inverse of the probability of selection. For example, in replicate 1, a total of 75 listings (including replacements) were selected from 1,297 listings in the sampling frame. The probability of selection was  $75/1,297$ , and the weight for each interview from replicate 1 was  $1,297/75$ .
- 2) Non-response weights account for the bias generated because respondents might differ from non-respondents systematically. For example, women might be easier to reach and are overrepresented in many surveys. If sex is related to the variable we are measuring, the mean or proportion computed from such data might be misleading. To create non-response weights, a characteristic that

is known for all sampled individuals, respondents or not, is used. However, in this case there was no such demographic characteristic known for all subjects. In some cases, not even area of residence or sex were known. The only thing that could be related to each and every listing was its origin. It could be known from which list each listing came. For example, a person may have entered the frame as a member of a church, as a friend of an individual, or as a client of an organization. Response rates were computed for each of the “lists” that composed the frame by dividing the number completed by the number sampled in each list. The inverse of the response rate was the weight for all respondents of that list.

3) Post stratification weights attempt to account for the bias that results from an imperfect sampling frame. It is usually based on a “gold standard” demographic distribution. In this case, the best data available were those of Census 1990, even though they were outdated. Demographic characteristics of the sample were compared to Census 1990 data. Preliminary weights were applied. These were the result of the multiplication of the design weights by the non-response weights. Since there was a great difference in the proportion of sampled individuals and Latinos in 1990 who lived in Allegheny, and who had more than high school education, and these variables were available in a cross-tabulated form from Census 1990 (U.S. Census Bureau, 1998), these variables were used to compute the weights. No comparable proportions were available for country of birth. This limited the weighting procedure, because country of birth appears to yield proportions likely to be different from the actual population proportions. Even when we have no comparable data, it is unlikely that South Americans represented such a large proportion of the Latinos in SWPA. The variables used to create weights were “county of residence”, coded “Allegheny” and “not-Allegheny” and educational level, coded as “high school or less” and “more than high school.” Separate two-by-two tables were constructed for Census 1990 data and preliminary weighted sample data, showing the number of people in each cell. The weight for each cell was the constant that, when multiplied by the cell value in the sample table, resulted in the corresponding cell value in the Census data table.

**Table 11****Selected demographic characteristics of the sample, Census 1990 data and Census Bureau estimates for Latinos in southwestern Pennsylvania**

| Age included               | Sample<br>18 + | Census 1990 <sup>a</sup><br>20+ | Estimates 1998 <sup>b</sup><br>20+ |
|----------------------------|----------------|---------------------------------|------------------------------------|
| <b>County of residence</b> |                |                                 |                                    |
| Allegheny                  | 88.8%          | 64.0%                           | 61.3%                              |
| Beaver                     | 1.0%           | 8.2%                            | 8.5%                               |
| Butler                     | 2.9%           | 4.0%                            | 4.7%                               |
| Fayette                    | 05%            | 3.4%                            | 3.5%                               |
| Greene                     | 0.5%           | 1.5%                            | 1.9%                               |
| Washington                 | 5.3%           | 8.9%                            | 9.3%                               |
| Westmoreland               | 1.0 %          | 10.0%                           | 10.7%                              |
| <b>Sex</b>                 |                |                                 |                                    |
| Male                       | 47.1%          | 47.7%                           | 46.8%                              |
| Female                     | 52.9%          | 52.3%                           | 53.2%                              |
| <b>Age</b>                 |                |                                 |                                    |
| 18-24 (or 20-24)           | 5.8%           | 19.4%                           | 11.0%                              |
| 25-34                      | 34.5%          | 28.7%                           | 23.6%                              |
| 35-44                      | 19.4%          | 19.3%                           | 22.6%                              |
| 45-54                      | 19.4%          | 13.1%                           | 14.5%                              |
| 55-64                      | 12.1%          | 9.9%                            | 11.5%                              |
| 65+                        | 8.7%           | 9.7%                            | 16.8%                              |
| <45                        | 59.7%          | 67.2%                           | 57.3%                              |
| 45+                        | 40.3%          | 32.8%                           | 42.8%                              |
| <b>Education</b>           |                |                                 |                                    |
| Age included               | 18 +           | 25 +                            |                                    |
| High school or less        | 23.8           | 49.18                           | n.a.                               |
| More than High school      | 76.2           | 50.82                           | n.a.                               |
| <b>Income</b>              |                |                                 |                                    |
| Type                       | Family         | Household                       |                                    |
| 50,000+                    | 30.2%          | 20.8%                           | n.a.                               |
| Median Income              | \$30-40,000    | \$25-34,900                     | n.a.                               |

n.a. = not available

<sup>a</sup> U.S. Census Bureau 1998<sup>b</sup> U.S. Census Bureau 2000

*d. Estimation*

Point estimates and 95% percent confidence intervals were computed for outcome variables for all participants and for groups divided by the “study variables,” income, acculturation and English proficiency. To obtain a better description of the population, point estimates and 95% percent confidence intervals of demographic variables were computed. Additionally, several estimates were computed by sex, income, acculturation and English proficiency, since they can affect socioeconomic status. Estimates can be found in Appendix 8 (Tables A7-A9 show the unweighted point estimates and the estimates computed after applying weights. Estimates by income, English proficiency, acculturation and sex are shown in tables A10-A27). Regional estimates were not computed due to scarce data. The program SUDAAN® was used to compute the estimates, since it has the capability to handle weights and incorporate them in the computation of the standard error, leading to more accurate confidence intervals. All three sets of weights were used to compute the estimates. Confidence intervals (CI) were computed as

CI: Estimate + /- Reliability coefficient ( $\alpha = 0.05$ ) \* Standard Error (SE)

Or

Lower limit CI= Estimate - 1.96 \* SE

And

Upper limit CI= Estimate + 1.96 \* SE

*e. Logistic regression procedure*

Logistic regression analysis was performed using the statistical package SUDAAN®. It was used to evaluate the effects of income, acculturation and (separately) language proficiency on the dependent variables, related to potential and realized access. The purpose of logistic regression was to explain what was observed rather than to predict the likelihood of an event to occur. For this analysis, only weights that accounted for probability of selection and non-response were used. Post-stratification weights were unnecessary, because

the regression was designed to account for most demographic variation by entering the “control” variables in the equation.

The data were cross-tabulated, and the relationship between the dependent and independent and control variables was evaluated. Zero-cells were found when cross-tabulating “region” and “insurance,” for the cell of “Puerto Rican, uninsured.” Other crosstabulations involving the variable “regions” showed cells with only one or two cases. Since multivariate logistic regression analysis would split the data into even more cells, the variable “regions” was recoded. South Americans comprised the largest group (92 individuals; weighted size 2,290). Of all groups, Mexicans were the ones with a greater percentage of people with lower income, fewer years of formal schooling, and lower English proficiency. There were 45 respondents in this group (weighted size 2,371). Therefore “regions” were further recoded into three groups: “Mexicans,” “South Americans,” and “Other.” The “Other” group brought together Puerto Ricans, Cubans, Central Americans and Others and was composed of 69 respondents (weighted size 2,271). It bears notice that this last group was created due to sample size constraints and not because the regions involved were considered homogeneous among themselves.

**Table 12****Variables to be included in logistic regression analysis**

| <b>Variable Type</b> | <b>Variable</b>                             | <b>Cate-<br/>gories</b> | <b>Coding</b>   |
|----------------------|---|-------------------------|---|
| <b>Dependent</b>     |   |                         |   |
| Potential<br>access  | Health insurance                            | 2                       | Yes: Any insurance<br>No: No insurance  |
|                      | Regular source of care                      | 2                       | Yes: Any regular source of care<br>No: No regular source of care                            |
| Realized<br>access   | Had a visit to the doctor in the past year  | 2                       | Yes: One or more visits in the past year<br>No: No visits in the past year                  |
|                      | Had a visit to the dentist in the past year | 2                       | Yes: One or more visits in the past year<br>No: No visits in the past year                  |
|                      | Satisfaction with care                      | 2                       | Low: “Moderately” and “Not at All” satisfied;<br>High: “Completely satisfied”               |
| <b>Independent</b>   |   |                         |   |
|                      | Income                                      | 2                       | Low: <\$20,000/ High: \$20,000 or more  |
|                      | Acculturation                               | 2                       | Low: <3 /High: 3 or more  |
|                      | English proficiency                         | 2                       | Low: Speaks Spanish better than English<br>High: Speaks English at least equally as Spanish |
| <b>Confounders</b>   |   |                         |   |
| Demographic          | Age   | 2                       | Young: 18 -44/Old: 45 and older   |
|                      | Sex   | 2                       | Male/Female   |
|                      | Origin                                      | 3                       | Mexican/ Other/ South American  |
|                      | Education                                   | 2                       | Low: Less than college/High: At least some college  |
|                      | Years in the U.S.                           | 2                       | Few: Less than 5 years/Many: 5 years or more  |
| Health needs         | Physical health status                      | 2                       | Bad: Below U.S. median /Good: U.S. median or higher   |
|                      | Mental health status                        | 2                       | Bad: Below U.S. median /Good: U.S. median or higher   |

Two criteria were used to consider variables for the regression equations. First, variables had to be relevant according to the conceptual model. Second, variables had to show a meaningful effect on the dependent variables. For this end, a set of univariate logistic regressions was performed for each dependent variable, including all theoretically relevant variables (see Table 13). The G statistic, as defined in Hosmer and Lemeshaw (1989), is the result of subtracting the Log Likelihood (LL) of one model minus the LL of another hierarchical model.

$$G = (-2 LL_{(\text{model with constant only})}) - (-2 LL_{(\text{model with constant and independent variable})})$$

The G statistic follows a Chi square distribution; the degrees of freedom correspond to the difference between the number of variables in the new model and the old model. In most cases, the G statistic followed Chi square with 1 degree of freedom; in the case of the variable “region,” that required 2 dummy variables to define it, the statistic followed a Chi square distribution with 2 degrees of freedom. Only if the probability that the relationship with the outcome was due to chance in less than 25% of the cases ( $p < 0.25$ ) the variable was considered for the multivariate regression. The value of 0.25 is arbitrary, but has proven useful for others, and it was suggested by the work of Bendel and Affi (as cited by Hosmer & Lemeshaw, 1989, p. 86). Hosmer and Lemeshaw explain that larger values usually lead to the inclusion of variables that are poorly related to the outcome and only add “noise” to the equation. Smaller values tend to leave out variables that may not seem significant in the univariate regression, but when taking into account other variables, become significant. Values for the G statistic in univariate regressions are shown in Table 13.

For each dependent variable separately, two sets of regressions were performed. The first one involved the independent variables “income” and “acculturation.” The second set involved the independent variables “income” and “English ability.” The covariates used in both cases were those selected as described above. The reason for having two sets of regression equations was that “English ability” was one of the questions of the acculturation scale. If both

variables were in the equation, “English ability” would be represented more than once. The variables “income,” “acculturation,” and “English ability” are referred to as the “study variables.”

The method of forward inclusion of variables was used to perform multivariate logistic regression. First, a logistic regression was performed that contained only the two study variables. Study variables were to stay in the model, regardless of their significance in determining the outcome, since they were directly related to the questions posed by the research. Next, a covariate was introduced. The covariate stayed in the model in two cases.

a) If it was shown with 95% confidence that the covariate's contribution to the model was not due to chance. This was ascertained by the G statistic, with p less than 0.05. The degrees of freedom were equal to the number of variables included (df = 1 in all cases, except when including “region”, where df=2).

$$G = (-2 LL_{\text{(model without covariate)}}) - (-2 LL_{\text{(model with covariate)}})$$

b) If the introduction of the variable caused a change of 15% or more in the value of the coefficient of at least one of the study variables, with respect to the previous model. The reason was that even if the G statistic was not significant, if the variable affected the way the study variables acted, it was contributing to define their effect. This rule was not valid for coefficients that were smaller than their standard error; these were considered too unstable and an important effect of the independent variable was not necessary to cause the coefficient to change considerably.

It is advisable to keep only relevant variables in the equation, because fewer variables make the model more parsimonious. This decreases the standard error, and increases stability of the coefficients and generalizability. A model with too many variables might be “overfitted.” This means it will be too dependent on the data observed. An added advantage is that a model with fewer variables becomes easier to understand and interpret. Some have argued that all theoretically relevant variables should be included in the equation, and no attempt should be made to achieve a more parsimonious model. This would allow for those variables that show no effect by themselves to show an effect in

combination. While this is quite possible, the other approach offers more advantages, as explained above (Hosmer & Lemeshaw, 1989).

After each variable was entered, the effect of the study variables was ascertained using the Wald statistic, which follows a z distribution with 1 degree of freedom and the confidence interval of the odds ratio.

The decision to include or eliminate a covariate was done by the analyst, as recommended by Hosmer and Lemeshaw (1989) as the preferred method, and without following any computer algorithm. After a decision was made regarding a covariate, the next covariate was entered. The first covariate entered into the equation was the one that showed the smallest probability for the G statistic in the univariate regression; the last one was the one that showed the largest probability, provided it was less than or equal to 0.25. The covariates that were also measures of access (“insurance status,” “source of care,” and “visit to the doctor”) were entered last, because it is known that potential access is a determinant of realized access. Some of the study variables could affect the dependent variable through a measure of potential access. For example, income and insurance status may both be determinants of whether or not the person has a usual source of care. However, income also determines insurance status. The effect of income over “source of care” may be exercised through “insurance status,” and could be thought of as,

Income → Insurance status → Source of care → Visit to the doctor

In this case, according to Andersen’s framework, we expected that the effect of income on “visit to the doctor” decreased or disappeared after “insurance status” was introduced.

Once a model with the main effects was developed, interactions were introduced as appropriate. To consider a potential interaction a) the interaction had to be theoretically plausible, and b) the two first order variables must have a significant effect on the outcome in the final main effects model, defined as a Wald statistic with a probability of less than 0.05.

**Table 13****Univariate logistic regression: Values of the probability that the G statistic is different from 0 by chance****Study variables and covariates**

| Dependent variable  | Insurance status | Usual source of care | Saw a doctor in the past year | Saw a dentist in the past year | Blood pressure measured in the past year | Satisfied with medical care |
|---|------------------|----------------------|-------------------------------|--------------------------------|--|-----------------------------|
| <b><i>Study variables</i></b>                             |                  |                      |                               |                                |  |                             |
| Income  | 0.00             | 0.00                 | 0.29                          | 0.04                           | 0.02                                     | 0.63                        |
| Acculturation English                                     | 0.75             | 0.00                 | 0.11                          | 0.07                           | 0.00                                     | 0.04                        |
| English   | 0.00             | 0.00                 | 0.76                          | 0.49                           | 0.13                                     | 0.45                        |
| <b><i>Covariates</i></b>                                  |                  |                      |                               |                                |  |                             |
| Region of birth   | 0.00             | 0.11                 | 0.99                          | 0.11                           | 0.57                                     | 0.35                        |
| Sex   | 0.67             | 0.14                 | 0.00                          | 0.05                           | 0.00                                     | 0.54                        |
| Age group   | 0.06             | 0.07                 | 0.54                          | 0.96                           | 0.31                                     | 0.46                        |
| Education   | 0.00             | 0.00                 | 0.38                          | 0.04                           | 0.01                                     | 0.04                        |
| Time in the U.S.  | 0.33             | 0.00                 | 0.24                          | 0.37                           | 0.08                                     | 0.97                        |
| PCS   | 0.32             | 0.79                 | 0.95                          | 0.09                           | 0.26                                     | 0.00                        |
| MCS   | 0.56             | 0.80                 | 0.52                          | 0.30                           | 0.75                                     | 0.02                        |
| <b><i>Covariates that are also measures of access</i></b> |                  |                      |                               |                                |  |                             |
| Insurance   | -                | 0.00                 | 0.01                          | 0.28                           | 0.00                                     | 0.88                        |
| Place of care   | -                | -                    | 0.00                          | 0.03                           | 0.00                                     | 0.92                        |
| Saw a doctor  | -                | -                    | -                             | 0.00                           | 0.00                                     | 0.37                        |
| Saw a dentist   | -                | -                    | -                             | -                              | -  | 0.65                        |
| BP measured   | -                | -                    | -                             | -                              | -  | 0.40                        |

G = (-2 Log Likelihood (model with constant only)) - (-2 Log Likelihood (model with variable))

The results of the univariate regression are summarized in Appendix 9. After the univariate analysis was performed, it was noted that the variable “source of care” had an effect on “blood pressure measurement” that was too high. The G statistic was 93, and the odds ratio of having a blood pressure measurement if the person had a visit to the doctor was 92.92, with a confidence interval between 31.12 and 277.11. Values so large point to a problem with numbers. In this case, the problem appears to be that most people had a blood pressure measurement at their visit to the doctor, and most of those who went to the doctor had a blood pressure measurement. Even when the standard error was not extremely large, this is a case of quasi-complete separation, which is described by Hosmer and Lemeshaw (1989). It can be seen more clearly in Table 14. Additionally, it can be noted that the number of cases in two of the cells is very low.

**Table 14**  
**Crosstabulation of variables “blood pressure measurement” and “visit to the doctor”**

|   |     | Visit to the doctor in<br>the last year |             |
|---|-----|---|-------------|
|   |     | Yes                                     | No          |
| Blood pressure<br>measurement<br>in the last year | Yes | 159<br>(4,132)                          | 8<br>(192)  |
|   | No  | 8<br>(162)                              | 30<br>(697) |

Numbers in parenthesis represent weighted totals. Weights are probability of selection and non-response.

After closer examination of the variable and of the literature related to measuring access to preventive care, this variable was dropped from the analysis. The literature suggests that nowadays most people get blood pressure

measurements, and this is not a good indicator of access to preventive care. Rather, most articles focus on measures such as Pap smears, breast exams, and/or mammography for women, and colorectal exams for men (Fulton et al, 1995; Himmelstein & Woolhandler, 1995; Martin et al, 1996; Pearlman et al, 1996; Polednak, 1996; Suárez, 1993).

“English ability” and “acculturation” showed coefficients that were smaller than their standard errors in the multivariate regressions, after one or two variables were added, and sometimes from the very first model containing only income and “English ability” or “acculturation.” This was more frequent in the case of the variable “English ability.” This variable represented the subject's own evaluation of his/her ability to speak English, and no objective measure of English ability was performed. However, some observations are of interest. Several times, the subject was observed while speaking English. Some who I observed to speak Spanish better than English, had stated that they spoke both languages equally. Since the statistical results point to instability in the coefficients, and the observations support the possibility that the variable “English ability” did not accurately measure language ability, it was dropped from further analysis. Only one set of regressions was performed for each of the outcomes: “insurance status,” “source of care,” “saw a doctor,” “saw a dentist” and “general satisfaction.” The results of all regressions were summarized graphically in Figure 4.

Insurance Status “Income” was found to significantly affect “insurance status,” in the univariate regression and also after controlling for “acculturation,” “region of birth,” and “education.” “Acculturation” had no significant effect, but was kept in the model since it was a study variable. “Education” and “region of birth” also had significant effects on “insurance status” in the final model. An interaction term involving “income” and “education” was considered theoretically plausible, since it was possible that more educated people made use of higher income to purchase insurance more frequently than less educated people. However, the interaction term was not significant.

**Table 15****Final results of multivariate logistic regression on variable “insurance status.”****Main effects model**

| Variable      | Coefficient | SE (Coeff.) | p (Wald) | Odds ratio | Confidence interval |
|---------------|-------------|-------------|----------|------------|---------------------|
| Income        | 1.91        | 0.47        | 0.00     | 6.78       | 2.66, 17.25         |
| Acculturation | -0.83       | 0.48        | 0.09     |            |                     |
| Region        |             |             | 0.01     |            |                     |
| Mexico        | -0.69       | 0.52        |          |            |                     |
| Other         | 1.05        | 0.57        |          |            |                     |
| Education     | 2.00        | 0.48        | 0.00     | 7.38       | 2.87,18.98          |

Only Odds ratios significantly different from zero are reported.  
For a complete description of all models, see Appendix 10.

Source of Care “Income” and “acculturation” both had a significant effect on “source of care” in the univariate regression, and in the multivariate, after controlling for “education”. However, after controlling for “time in the U.S.,” the effect of both variables decreased, especially that of “acculturation.” “Income” was almost significant, until “insurance status” (which, from the previous set of regressions, we know was determined by “income”) was introduced. “Time in the U.S.” and “insurance status” were the only significant determinants of having a source of care with an odds ratio greater than “1.” “Education” and “sex” did not show odds ratios different than “1,” but were kept in the model because they changed the value of the coefficient of the study variables in more than 15%. After the main effects model was ready, a next model without “time in the U.S.” was calculated, where “acculturation” showed a significant effect on “source of care,” with an odds ratio of 4.1 (95% confidence interval 1.29-12.96).

**Table 16****Results of multivariate logistic regression on variable “source of care.” Main effects model**

| Variable         | Coefficient | SE (Coeff.) | p (Wald) | Odds ratio | Confidence interval |
|------------------|-------------|-------------|----------|------------|---------------------|
| Income           | 0.26        | 0.48        | 0.60     | 1.29       |                     |
| Acculturation    | 0.84        | 0.60        | 0.16     | 2.32       |                     |
| Education        | 0.57        | 0.56        | 0.30     | 1.78       |                     |
| Time in the U.S. | 1.53        | 0.52        | 0.00     | 4.61       | 1.67, 12.79         |
| Sex              | 0.74        | 0.47        | 0.11     | 2.10       |                     |
| Insurance status | 1.75        | 0.52        | 0.00     | 5.75       | 2.07, 15.98         |

Only Odds ratios significantly different from zero are reported.  
 For a complete description of all models, see Appendix 10.

An interaction term between “insurance status” and “time in the U.S.” was significant in reducing the odds of having a usual source of care, with a G statistic with 1 degree of freedom of 5.82. This means that the effect of not having insurance on having a source of care is different for a person who has been in the U.S. for less than five years than a person who has been here longer. In conclusion, “insurance status” and “acculturation” have no significant effect on “source of care” after controlling for “education,” “time in the U.S.,” “sex,” and “insurance status.” Acculturation seems to act in relationship with “time in the U.S.,” and “income” affects “source of care” through “insurance status.” A negative interaction between “insurance status” and “time in the U.S.” exists. This means that for a person with less than 5 years in the U.S., the probability of being insured increases with income faster than for a person with 5 years or more in the U.S. In other words, the curve of insurance versus income is steeper in those who have been in the U.S. for less than 5 years. This is apparently contradictory, but the curve is flatter for those with more years here because those with low income have naturalized, have arranged for low-cost care options, and/or found a job that offers insurance.

**Table 17****Results of multivariate logistic regression on variable “source of care.” Model with interactions**

| Variable                            | Coefficient | SE (Coeff.) | p (Wald) | Odds ratio | Confidence interval |
|-------------------------------------|-------------|-------------|----------|------------|---------------------|
| Income                              | 0.27        | 0.49        | 0.58     |            |                     |
| Acculturation                       | 0.84        | 0.56        | 0.14     |            |                     |
| Education                           | 0.67        | 0.57        | 0.24     |            |                     |
| Time in the U.S.                    | 3.07        | 0.90        |          | 21.52      | 3.62, 128.97        |
| Sex                                 | 0.68        | 0.48        | 0.16     |            |                     |
| Insurance status                    | 3.21        | 0.85        |          | 24.75      | 4.61, 132.97        |
| Insurance status * time in the U.S. | -2.34       | 1.03        |          | 0.10       | 0.01, 0.74          |

Only Odds ratios significantly different from zero are reported.  
For a complete description of all models, see Appendix 10.

Visit to the Doctor “Income” and “acculturation” both had no significant effect on “visit to the doctor” in the univariate regression, or in the multivariate, after controlling for “sex,” “insurance status,” and “source of care.” “Sex” was a significant determinant of “visit to the doctor” and it kept its effect after the introduction of “insurance status” and “source of care.” “Insurance status” had a significant effect when it was introduced, but it lost its effect after the introduction of “source of care.” This makes theoretical sense, because “insurance status” determines “source of care.” An interaction term between “sex” and “source of care” was introduced in the model, but it had no significant effect on the dependent variable.

**Table 18****Results of multivariate logistic regression on variable “visit to the doctor.”****Main effects model**

| Variable         | Coefficient | SE (Coeff.) | p (Wald) | Odds ratio | Confidence interval |
|------------------|-------------|-------------|----------|------------|---------------------|
| Income           | -0.43       | 0.47        | 0.37     |            |                     |
| Acculturation    | 0.12        | 0.52        | 0.82     |            |                     |
| Sex              | 1.81        | 0.50        | 0.00     | 6.14       | 2.28, 16.52         |
| Insurance status | 0.75        | 0.49        | 0.13     |            |                     |
| Source of care   | 1.91        | 0.53        | 0.00     | 6.73       | 2.35, 19.32         |

Only Odds ratios significantly different from zero are reported.  
 For a complete description of all models, see Appendix 10.

Visit to the Dentist “Income” and “acculturation” both had no significant effect on “visit to the dentist” in the univariate regression, or in the multivariate, after controlling for “education,” “sex,” “region,” “insurance status,” and “source of care.” No variables had a clear-cut significant effect on “visit to the dentist.” However, in the final model “source of care” had an almost significant effect (Wald statistic's  $p=0.05$ ); the odds ratio's confidence interval included zero, but it was skewed to the right (0.99-5.77). Other covariates stayed in the model because they changed the coefficients of the study variables more than 15%.

**Table 19****Results of Multivariate Logistic Regression on Variable “visit to the dentist.”****Main effects model**

| Variable         | Coefficient | SE (Coeff.) | p (Wald) | Odds ratio | Confidence interval |
|------------------|-------------|-------------|----------|------------|---------------------|
| Income           | 0.45        | 0.41        | 0.27     |            |                     |
| Acculturation    | 0.49        | 0.39        | 0.22     |            |                     |
| Education        | 0.49        | 0.42        | 0.24     |            |                     |
| Sex              | 0.44        | 0.37        | 0.24     |            |                     |
| Region           |             |             | 0.08     |            |                     |
| Mexico           | 0.43        | 0.54        |          |            |                     |
| Other            | -0.66       | 0.44        |          |            |                     |
| Insurance status | 0.25        | 0.46        | 0.59     |            |                     |
| Source of care   | 0.87        | 0.45        | 0.05     | 2.39       | 0.99, 5.77          |

Only Odds ratios significantly different from zero, or almost significantly different are reported. For a complete description of all models, see Appendix 10.

General satisfaction “Income” and “acculturation” both had no significant effect on “general satisfaction” in the univariate regression, or in the multivariate, after controlling for “education.” “Mental health status,” “time in the U.S.,” and “source of care” did not show a significant effect on “satisfaction”. Education had a significant negative effect: the more educated respondents were less likely to be satisfied. No interactions were introduced, because only one variable was significant at the 95% confidence level. The measure of satisfaction used here corresponded to a question in the survey about satisfaction with services received, in general. There were nine other questions asked about specific dimensions of satisfaction. Since the ten questions did not constitute a scale, they were not added. However, some analysis was made to shed light on what did people talk about when they answered the question about satisfaction in general. For this, a set of univariate regressions tested the effect of each of the nine specific variables on “general satisfaction.” All had a significant effect.

Later, a multivariate model was fit that included all nine variables as independent ones. Four of them showed a statistically significant effect ( $p < 0.05$ ). They were “satisfaction with doctor’s treatment,” “satisfaction with waiting times,” “satisfaction with language spoken,” and “satisfaction with information received.” It is likely that the subjects that were “moderately” or “not at all” satisfied in general, were mostly “moderately” or “not at all” satisfied with these four dimensions. The results of those regressions are in Appendix 11.

**Table 20**  
**Results of multivariate logistic regression on variable “general satisfaction.”**  
**Main effects model**

| Variable       | Coefficient | SE (Coeff.) | p (Wald) | Odds ratio | Confidence interval |
|----------------|-------------|-------------|----------|------------|---------------------|
| Income         | 0.16        | 0.42        | 0.70     |            |                     |
| Acculturation  | 0.59        | 0.35        | 0.09     |            |                     |
| Education      | -1.25       | 0.47        | 0.01     | 0.29       | 0.11 - 0.72         |
| Source of care | 0.81        | 0.45        | 0.07     |            |                     |

Only Odds ratios significantly different from zero are reported.  
For a complete description of all models, see Appendix 10.

*f. Limitations of the analysis*

This research is concerned with Latinos in southwestern Pennsylvania (SWPA). It describes this population and analyzes relationships among variables relevant to health care access within that population. There is a less formal attempt to compare this group with other Hispanic groups in the United States. However, caution should be exercised in two areas. First, these data do not allow us to generalize the results to the Latino population of the United States or even the state of Pennsylvania. Second, no claim is being made that the characteristics of this group are exclusive of Latinos. Many of the same

characteristics might be found in other groups both within and outside of the United States.

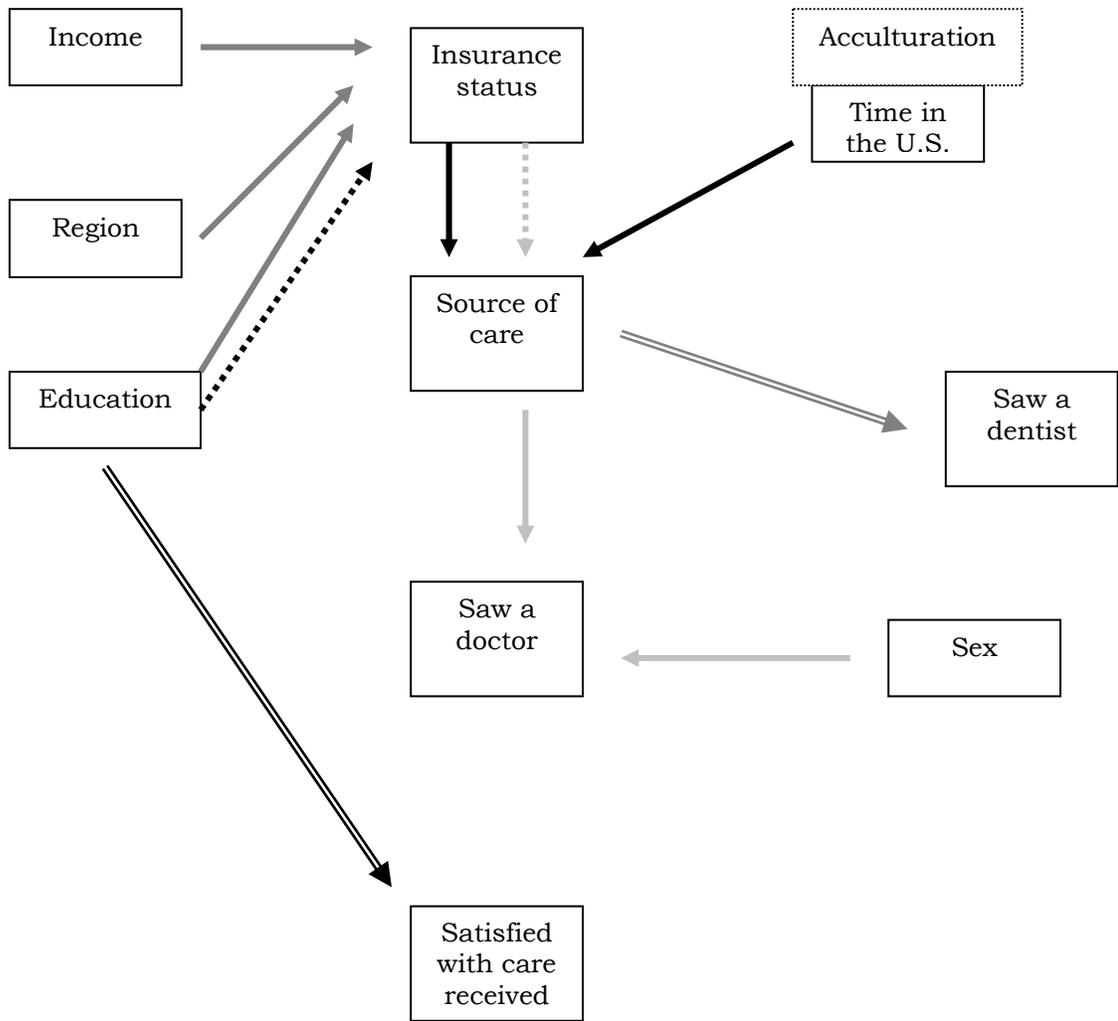
The data presented here have been acquired during field research, either through participant observation, informal conversations and/or survey research. All information is derived from such data, unless a bibliographical source is specifically cited. Results of data from quantitative and qualitative sources have been integrated to give a more complete picture of the issues under study.

The most serious limitation of this study was that not all Latinos in SWPA had an equal opportunity to enter the sampling frame for the survey or to take part in participant observation. The incomplete sampling frame forces us to interpret statistical results with care. The primary limitation of participant observation methods, and of ethnographic research in general, is that they do not allow generalizing easily, as explained by Weiss (1994). However, using participant observation together with survey research allowed me to clarify some of the findings of the survey and also served to suggest new lines of inquiry.

Another limitation of the analysis is that a “negative” result, or the result that a variable has no significant effect on the outcome, has to be taken cautiously. For the different analysis pieces, a conservative approach was used and the finite population correction (fpc) was ignored. This decision was made since the size of the population, estimated at around 17,500 (N), was large in relation to the sample of 206 (n). The fpc, defined as  $(N-n)/N$  (Scheaffer et al, 1996) was close to unity. However, ignoring the fpc adds approximately a 9% increase to the variance. Therefore, if an estimate were significant, this feature would not affect the result. However, one should take cautiously any non-significant result, because an increased variance would result in a wider confidence interval.

Additionally, there were other limitations. They included that the weighing process might not have accounted for all the bias introduced by an imperfect sampling frame and that the measurements themselves might be inaccurate. It is easy to measure things such as country of birth. However, acculturation is a much more difficult issue. Culture encompasses too many

dimensions. Even when the scale used had been validated before, it only measured those dimensions that the creators tried to measure. Other dimensions are place of birth, age at migration, generation and some “characteristics” of Latinos, connection with ethnic institutions, or celebration of ethnic festivities (Giachello, 1996 a; Negy & Woods, 1992). There were some variables that might be important (for example, immigration status) that were not explored at all. A relatively small number of subjects made it impossible to offer separate estimates by Latino subgroup, even though we know there are significant differences among those subgroups.



Legend:

Solid line: significant effect in the final model

Broken line: significant effect that may follow this path (erased after next variable was entered)

Regression on:

Insurance status

Source of care

Saw a doctor

Saw a dentist

Satisfied with care received

**Figure 4**  
**Summary of results of logistic regression**

### ***E. Definition of Terms***

Latino/Hispanic: It is determined by self-identification, using the Office of Management and Budget (2001) definition: “a person of Cuban, Mexican, Puerto Rican, South or Central American, or other Spanish culture or origin, regardless of race”. The terms “Latino” and “Hispanic” are used as synonyms.

Geographic area: southwestern Pennsylvania (SWPA), including 7 counties: Allegheny, Beaver, Butler, Fayette, Greene, Washington and Westmoreland.

Anglo: This definition includes all U.S. nationals that are not Latinos, especially those of European origin.

U.S. citizen: A person who is a U.S. national.

American: In the United States this designates a U.S. national. The same word, used in Latin America and other parts of the world, designates any person from the Americas. Due to this inconsistency, and to avoid being insensitive to either population, this word was not used regularly in this research.

Adults: They are people 18 years or older.

Children: For the purpose of the study, only children of Hispanic parents at least 2 years old but younger than 5 years old are considered.

Access: It is defined as potential and realized (Aday et al, 1984).

Potential Access: Having a regular source of care (doctor or place) and having health insurance. Both measures have been used in previous studies (Aday et al, 1984).

Realized access for adults: Having seen a doctor in the past year, having seen a dentist in the past year, having had a measure of blood pressure in the past year and being satisfied with the care received (Aday et al, 1984).

Realized access for children: Having seen a doctor in the past year, having current vaccinations and parental satisfaction with care received (Aday et al, 1984). Between 2 and 5 years old children must have all required immunizations, yet they have not entered school (when immunization requirements will be enforced.)

## ***F. Common Abbreviations***

ACHD: Allegheny County Health Department

CDC: Centers for Disease Control and Prevention

CPS: Current Population Survey

DHHS: Department of Health and Human Services

HHANES: Hispanic Health and Nutrition Examination Survey

HRSA: Health Resources and Services Administration

NCHS: National Center for Health Statistics

MEPS: Medical Expenditure Panel Survey

NHIS: National Health Interview Survey

NMES: National Medical Expenditure Survey

NSFH: National Survey of Families and Households

SWPA: southwestern Pennsylvania

## **IV. The social context**

### ***A. Introduction***

Non-medical factors are known to affect health and health care access more than medical factors (Aday et al, 1998). It is important to see healthcare in a wider framework, as it is inextricably bound with the entire sociocultural context. Therefore, I will first describe the Latino population of southwestern Pennsylvania (SWPA) to set a background against which to understand its current health care access conditions. The description will include a brief history, geographical distribution, migration patterns, and cultural characteristics, as well as socioeconomic status. A cohesive community constitutes a source of social capital and may take a stand to protect the rights of its members. For this reason, this chapter is also preoccupied by the task of answering a question that has important repercussions for health and health care access: Is this a cohesive community? For this purpose, several indicators of community are explored, such as number of people, geographical concentration, homogeneity, ethnic identification, community organization, and group solidarity.

### ***B. History***

Southwestern Pennsylvania (SWPA) always had a very small Latino population (U.S. Census Bureau, 2000). However, this population is not as new as we might think. According to the accounts of several Latinos in this area, early this century Mexicans and Spanish people came here to work in the railroads and in the steel mills. A few small Spanish speaking communities

flourished in the area. For example, in Donora, Allegheny County, there were enough people to have a community center where, at least until a few years ago, activities were held. The lyrics of a Mexican-style musical piece, *Corrido de Pennsylvania*, talk about work on the railroad. However, for the most part, there was great pressure to integrate with the much larger European American community. Most Latinos learned English and used it both on the street and at home. Many intermarried and, eventually, cut their ties to their country of origin. To this day, some of the descendants of these people consider themselves to be Mexicans and/or Hispanic, even though they do not speak Spanish and have never been to Latin America. The timing of the arrival of these Latinos in the area and their subsequent assimilation is not surprising; it happened at a time when foreign immigrants and Southwest Hispanics worked in industry and railroads across the country (Gonzalez, 2000; Trueba, 1999).

By the 1950s, several Puerto Rican families had arrived in SWPA, but I could find no evidence of a concentration of Puerto Ricans in any particular area. An unpublished paper on geographical distribution of Latinos in Allegheny County by Patrick (1973) described a group of Latinos that could trace their origins to different countries in South America and the Caribbean. It also documented the existence of at least two “groups” of Latinos during the seventies. At that time, most Latinos were isolated from each other. For a time, a small group of educated Hispanics –several of which had ties to the local universities– would get together to socialize and discuss cultural issues. Another group, whose members had lower incomes and fewer years of formal schooling, was located in the North Side and faced unemployment problems. At some point, a pastor from the North Side group approached the university-related group for help finding jobs for his people. According to Patrick, this contact did not produce any results because the interests of the university-related group were mostly cultural, and the two groups continued as separate as before.

### **C. Geographical distribution**

At the time of this research, most Latinos in SWPA lived in Allegheny County. In the sample surveyed, Mexicans were the ones most frequently located outside of Allegheny. As in the rest of the United States, Latinos in SWPA tended to be concentrated in urban areas (Chavez et al, 1992; Marin & VanOss Marin, 1991). However, in most U.S. cities there are geographic concentrations of low income Hispanics, called *barrios* (Baker et al, 1997; DeSantis & Halberstein, 1992; Erickson, 1994; Flores WV, 1997 a; Freidenberg & Hammer, 1998). Latinos in SWPA are scattered; there is no barrio and never has been one. This feature had important implications for community formation, for the dissemination of information and for access to health services, as will be seen later.

However, even in the absence of a *barrio*, Latinos seemed to prefer certain areas to live in. Many of the newcomers, who worked in services, could be found in Oakland, the South Side, Lawrenceville, and East Liberty. People related to the university tended to live in Oakland, Shadyside and Squirrel Hill. Several informants believed there were people of Puerto Rican ancestry that were mostly of African descent and lived in subsidized housing. They were difficult to find, because they did not associate with the universities or with the Mexicans that worked in the service sector. They spoke mainly English, and most people would not be able to distinguish them from African Americans, unless they volunteered information about their ethnic origin. I was able to find three different individuals who fit this description. Two lived in the inner city in two separate areas, and the third worked for a university, having grown up in a local housing project. In rural areas, Latinos were found in Washington and Butler County, around farms, and they were mostly (but not exclusively) Mexicans. The work by Patrick (1973) talks about the absence of a geographic concentration of Hispanics, but notes that the more “connected” tended to live in the east section of Pittsburgh.

#### ***D. The road to SWPA***

Only 20 (9.7%) of SWPA Latinos surveyed had been born in the U.S. (those born in Puerto Rico were not counted here). Twenty two percent of Latinos had been in the U.S. for fewer than 5 years, but the length of stay varied from less than one year to fifty years. Latinos came to SWPA for varied reasons, and that partially explained the variations in the proportions of them that have been in the U.S. for a short time. Very, very few came to work for a company in a position with high salary. Some, more often women, arrived after they married a person who lived in the area. The most frequent road to SWPA was related to migratory patterns of Latinos in the United States in general, as well as to migratory patterns from the specific country of origin (Gonzalez, 2000; Rocco, 1997; Trueba, 1999). Many Puerto Ricans migrated to the continental U.S. some 50 years ago, when the U.S. needed workers (Gonzalez, 2000; Trueba, 1999). Eventually some of them arrived in SWPA. They were U.S. citizens, and therefore, did not face the immigration obstacles other groups faced. Among the people surveyed, Puerto Ricans and Others were the ones that had been here the longest.

Many Mexican families had been here for many years, often since the days of the steel mills and railroads (Patrick, 1973). Since the early to mid-nineties, a new wave of Mexican immigrants has been arriving in SWPA. Today, as in the past, those who come to rural areas work in agriculture; those who come to the cities work in service occupations, such as kitchen help. Their migration follows a well-established path, as connections exist between the employer in SWPA and the place of origin. When immigrants arrive, they know they have a job, even though some might not have a clear migratory situation. Males tend to migrate first. It is common for people who work at the same place to have come from the same village, or same Mexican state. Frequently, they have relatives in the area: brothers, cousins, and uncles. Migrants continue coming every year until they save enough money to establish themselves in Mexico or decide to stay here. At that point, if not sooner, they usually bring their family to the area. As time passes, they try to bring more of their kin to live here. For example, Juan came to work in services, and later, his brother

joined him. After five years, Pura, his wife, came too. The couple worked six days a week for a year, until they saved enough to send for their children. As one woman put it, "*Traen al hermano, al primo, al otro...ya todo el pueblo está aquí*" ("They bring the brother, the cousin, the other one...now all the village is here"). This story was very common throughout the U.S., for urban and rural migrants alike (Gonzalez, 2000; Trueba, 1999; Zsembik & Beeghley, 1996). Several people I spoke with said that the main reason the first person in a family group came to SWPA was a relatively competitive income for service jobs. However, for the relatives who followed, family ties might have been equally or more important.

Many Cubans I met during this research came to SWPA between 35 and 40 years ago, with the first waves of Cuban immigrants that fled the Castro regime. They are now, for the most part, well established. A few came after 1980, with the Mariel boatlift, and their economic situation is not as favorable. However, a sizable group of Cubans are new immigrants. This explains why, in the sample surveyed, Cubans were the "newest" group. They came as refugees and were assigned to SWPA by the agency that sponsored them. Their migratory situation was quite clear, and through the Cuban Adjustment Act (*ley de ajuste cubano*) (DeSantis & Halberstein, 1992), they could not be deported. They were granted permanent residency after one year of residency in the U.S., and could attain citizenship in shorter time than other Latin Americans. Upon arrival, they were provided housing and health care for some time, but then they were on their own. As did Mexicans, Cubans tended to live close to their family members. Interestingly, many of these new arrivals tended to migrate to areas with a larger concentration of Cubans, such as Florida, as soon as they were able to do so.

Middle class people of any country frequently arrive as graduate students or postdoctoral fellows. Many stay after their initial study period ends. At the time of this study, some had been here 10, 20 or 30 years and were well established now. Newer graduate students find it more difficult to stay, due to tougher immigration laws. Therefore, they accept odd jobs until they clear their migratory situation. Quite a few Latin American physicians came for post-

graduate training and stayed. There are many Latino doctors in the area, from almost every country in Latin America.

Other Latinos followed a less established migratory pattern. Some came as tourists, with or without the intention to stay. Others came as students. After some time, their visas expired, and they found themselves searching for a legal way to remain in the U.S. Many succeeded, but the process might have taken years. This is common for many immigrants in the U.S. (Chavez et al, 1992). There are also some immigrants peculiar to the Pittsburgh area. A few families came when a member of their family needed a transplant. Some of those families stayed for years, as many as 5, 10 or even 20.

Relative to other areas in the U.S., SWPA has an “excess” of South Americans. According to Gonzalez (2000) and Rocco (1997), Latin American immigrants came to the U.S. in greater numbers from places where the U.S. had more economic, cultural or military ties. For example, long-term economic enclaves in Central America displaced workers and also created cultural relationships, and the people in those areas looked to the U.S. as their ideal. Additionally, military interventions in those countries strengthened those ties. Most of the migrants from these areas were working class people. Even though relations with the geographically more distant South America existed, they were not as strong as those with Mexico, Cuba, Puerto Rico and Central America. Wilson (1998) argues that the economic crisis of the 1970s and 1980s, which led to economic decline and population loss in SWPA, precluded many working class immigrants coming to this area. Therefore, the “excess” of South Americans might be only relative. They came in the same numbers they did to other cities in the U.S., but the working class immigrants, where people from Mexico, Puerto Rico and Central America are often overrepresented, did not migrate here.

It is a common mistake, stemming from a stereotype of Latinos, to think that most undocumented migrants are Mexicans or that most Mexicans are undocumented. In fact, many Latinos of Mexican descent were born in the U.S. or were legal immigrants, and many immigrants from other countries might have an unstable migratory status. According to Chavez et al (1992), Latino immigrants from different countries are diverse in their reasons for migration

and the means they use to arrive in the U.S. What was more or less constant about most Latinos in SWPA is that, once they are here, they associate with other connationals or with people from other countries in Latin America, and they make every effort to bring their families.

### ***E. Family Structure***

Latino families in SWPA are varied. According to Census 1990 data (U.S. Census Bureau, 1998), 52% of Latinos lived in households headed by a married couple, 15% in families with a single parent, and 33% in non-family households. Participant observation data corroborated that most frequently Latino households were headed by a married couple. Perhaps the most frequent type of family was the nuclear one. Some families had a single parent, usually a single mother. Several families included additional members, such as brothers, sisters, parents or aunts of the householder. Sometimes adult nephews or nieces lived with a family, either temporarily or permanently. Some grandparents took in grandchildren with or without the parent. When Latino young people went to college, it was common to find that they attended a college nearby and spent many, if not all weekends, with their families. Several adult children continued living with their parents, even when income was not an issue. Quite often, families had relatives as guests. Visits were usually long, and they might last several months, especially when the guests were the retired parents of adult children. For example, Ana visited her daughter every year, and stayed for 8 months each time. Family guests or other adult members who did not work outside the home, collaborated with the household by doing housework or babysitting. In a few cases, this relationship looked more like that of a maid and a *patrona*. In others, it was like a mother helping out an adult child and would be a common role of a family member in Latin America. These different combinations were found in families from several areas, such as South America, the Caribbean, and Mexico.

Some Latinos, especially those who migrated alone for employment, frequently lived together in homes with other immigrants as roommates. In some cases, up to 7 or 8 roommates lived in the same house, and they often

shared a phone. Students also tended to live with roommates, but they usually each had separate phone numbers. Frequently Latinos here, as reported by Erickson (1994) for the rest of the U.S., were mobile. They changed homes and living arrangements quite often. This was more marked among migrants with fewer years of formal schooling and lower incomes; it is more frequent among all people with those characteristics, Latinos or not. However, frequent change of residence might be more common for Latinos and other immigrants than for Anglos of low income because several of them might have an uncertain immigration status.

Latinos of rural origin tended to come from larger families than those from urban areas. Once here, they tended to have smaller families, with 1 to 3 children, and, more uncommonly, 4 or more. Adult Latinos might marry a person from the U.S. or another immigrant. It was not rare to see couples of Latinos from different countries that had met and married in the U.S. Hispanics in SWPA, like those across the U.S., appreciate extended families and the living arrangements that include them, although people were not unanimous on the latter (Erickson, 1994; Furino & Sumaya, 1992; Pérez-Montijo et al, 1996). Like Hispanics elsewhere, I found that Latinos in SWPA tended, as much as possible, to live close to sisters, parents, or grown children. They frequently visited and interacted with one another. For many, the family was at the root of being Latino, much more so than the language they spoke. One U.S. native, English-speaking Mexican, said that for him the difference between him and Anglos was that “[he] know[s] my family.” He described his extended family as a source of social life, role models, emotional and even economical support. For Gonzalo, a retired professional, family was “*lo primero*” (“the first thing”). He said that we, Latinos, must preserve our families, because lack of strong family ties are at the root of this society’s problems. Others did not say explicitly that their family was their main ethnic characteristic. However, the importance of family was expressed during countless conversations, as people described giving considerable weight to their relatives’ opinions when making important decisions, taking care of extended family members when they were sick or old, receiving them in their house for variable

periods of time (sometimes even years), and relating socially to their families with great frequency.

When people did not have their extended family members in SWPA, they tried to bring them to the area and/or to develop fictive kin ties. A fictive kin was a set of connections, a network of people who saw each other regularly and helped each other with necessary tasks (i.e., babysitting, moving, and finding housing and furniture.) They formed relationships of reciprocity, similar to those in families, particularly Latino families. An example of this was Irma. Irma was concerned that her son, a young adult, had “no family here.” She was used to having a large extended family to rely on for support and social interaction. Irma said she was now, like Anglos, with all her relatives living out of town. To ameliorate this problem, she tried to develop close ties with other Latinos in the area, so that they could be “like *mi familia*” (“like [her] family”).

Others established *compadrazgo* (godparenthood) ties, assuring a more formal relationship with fictive kin. This has been described about Hispanics in the U.S. several times, by authors such as Freidenberg and Hammer (1998), Keefe (1980), Saint-Germain and Longman (1993), Trueba (1999). For Latinos in SWPA, as described by Saint-Germain and Longman (1993) elsewhere, family, as an operating network, includes both blood relatives and fictive kin.

Many Latinos in SWPA believe that elderly people should continue to live home, even when their health declines, since quality of life is better at home. Many informants voiced their dislike of nursing homes. Personally, they would feel they had been “dumped” if placed in such an institution. Some pointed out that elderly people could remain at the home of extended family, because they could be useful taking care of grandchildren. This attitude has been observed before in other cities in the U.S. as a characteristic of Mexican and Puerto Rican Latino families (Bassford, 1995; Ruiz, 1992; Ruiz, 1995). Wallace et al (1995) used data from the National Center for Health Statistics (NCHS) 1988 Longitudinal Study on Aging, to conclude that Latino elderly were more likely than non-Latino White elderly to live with their adult children or “other family.” In SWPA, women tended to be the primary caregivers of the family. In some cases, they assumed the responsibility of taking care of elderly or disabled non-family members that were close friends. In some cases, no woman in the

household could take care of an elderly family member, due to working full-time. In those cases, even though they did not like it, they had to put their elderly relatives or friends in nursing homes. In the same way, many Latinos tended to dislike child care centers. Their use, however, was more widespread, perhaps due to lack of available grandparents locally or to the temporary nature of a child care center arrangement.

### ***F. Jobs and Income***

In general, Latinos in SWPA were not poor. Almost half of Latinos in SWPA had an annual family income under \$20,000 (See Table 21). The proportion of Latinos with lower English proficiency that had an annual family income under \$20,000 was 68.1%, significantly higher than the corresponding proportion for Latinos with higher English proficiency. However, even when the differences by English proficiency were significant, there were no significant differences for those who had lower and higher acculturation.

According to Becerra and Zambrana (1985), on average, Latinos in the U.S. are economically and socially disadvantaged. Burciaga Valdez et al (1993) add that poverty persists even in two-parent working families. At the national level, on average, Cubans are the wealthiest and Mexicans the poorest. These differences might be explained by the large number of Cubans from the more educated first wave of immigrants, which came to the U.S. in the 1960s and settled in Florida and parts of New Jersey (Fox, 1996; Trueba, 1999). By contrast, new refugees, who tend to have lower income, are distributed throughout the country by the agencies that sponsor them. Regional groups in SWPA were not homogeneous regarding income. For example, the person likely to be the wealthiest interviewee in this study was a Mexican.

Regarding occupations, around a third of Latinos in the sample worked in “blue collar, service and farm occupations.” A similar proportion worked in “professional or technical skilled occupations” or were “not in paid workforce” (See Table 22). Only 9.9% were primarily students.

There are many well-established Hispanic professionals in SWPA, including doctors, executives, engineers, and university professors who have

been in the area for many years. There are other professionals who are not as well established, and change jobs more frequently. Some have entered commercial endeavors, and a few fared well. Others continue doing “temporary” jobs for a long time. Others would change their current job, but they cannot, due to their particular visa situation. Some feel trapped in a particular job. This is one reason why income is low relative to level of education.

**Table 21**  
**Income of Latinos in southwestern Pennsylvania by English proficiency and acculturation. Weighted estimates and confidence intervals**

|  | Percentage with<br>annual family<br>income < \$20,000 | 95% Confidence<br>interval |
|--|---|----------------------------|
| All                                    | 49.6  | 35.4 - 63.7                |
| Latinos with lower English proficiency | 68.1  | 52.7 - 83.5                |
| Latinos with high English proficiency  | 23.8  | 10.8 - 36.7                |
| Latinos with lower acculturation       | 52.6  | 42.0 - 63.3                |
| Latinos with high acculturation        | 46.2  | 17.3 - 75.0                |

Weights for probability of selection, non-response, and post-stratification were applied.

Latinos who came to the area without an arranged job usually relied upon help from others who had been here longer, and might know how to find a job “under the table.” Some immigrants came specifically to work in services, such as restaurants, for example. They worked up to eleven hours a day six days a week and often lived with fellow workers. Sometimes they rented apartments in different parts of the city, but more frequently they lived in a house provided by the *patrón* (boss). The latter situation has been observed elsewhere, and, as pointed out by Trueba (1999) and Gonzalez (2000), it gives way to several exploitative relationships that are beyond the scope of this study.

**Table 22****Type of occupation of Latinos in southwestern Pennsylvania. Weighted estimates and confidence intervals**

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|  | Percentage in<br>occupation | 95% Confidence<br>interval |
|--|-----------------------------|----------------------------|
| Blue collar, service and farm occupations        | 32.5                        | 21.6 – 43.4                |
| Professional or technical skilled<br>occupations | 28.2                        | 18.9 – 37.6                |
| Not in paid work force                           | 29.4                        | 11.5 – 47.3                |
| Primarily Students                               | 9.9                         | 5.6 – 14.2                 |

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Weights for probability of selection, non-response, and post-stratification were applied.

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Several interviewees and people with whom I held informal conversations worked two, or even three, jobs. Some, for example, clean homes during the day and clean offices at night. This leaves little time for rest or any activities outside of work and little time to connect with people in the community. Others worked 11 or 12 hours shifts six days a week, especially as kitchen help. People who worked in restaurants were typically not allowed to tend tables, so they had no access to tips. Service jobs seldom provided benefits, such as vacation or insurance. Why did people tend to work odd jobs that were unstable and were changing frequently? Often, Latinos who worked in service jobs had few years of formal schooling. This has been described elsewhere by Burciaga Valdez et al (1993) as a cause of persistent low income. The jobs that attract immigrants are the lowest paying in the U.S. and therefore, the least competitive. Even so, these jobs still offer higher pay than any job available to that person in his/her country of origin (Giachello, 1996 b). Additionally, in SWPA it was not rare to find Latinos of middle class extraction that did not have a college degree, did not speak English well or might have an uncertain immigration status in the U.S., working in service occupations or in temporary jobs (i.e., cooking, catering, babysitting, cleaning, plastering, painting, pizza delivery, translation,

singing and playing music in bands.) However, they related to the middle class group and tried hard to live in areas that were considered middle class. Often, professionals in SWPA earned incomes that were low relative to their level of education for several years; some even worked in services or construction. They felt they had no other chance, due to a need to master the language and get some retraining in their field. Burciaga Valdez et al (1993), Gonzalez (2000), and Trueba (1999) report similar occurrences at the national level. They add that an unstable immigration status compounds the problem. Even when facing all these difficulties, many of these workers send remittances to their countries, which are crucial to the subsistence of their families back home (Gonzalez, 2000; Trueba, 1999).

In rural areas, there are many Latinos that work in agriculture or landscaping. A few live in SWPA year-round, but most frequently they come during the summer months then migrate back to their place of origin. The next year, some of the same workers return, together with new ones. These workers tend to be predominately males. They usually live in quarters provided by the *patrón* (employer) and relate with the local community. This is, with the other Mexicans who work for the same *patrón*. Females are also employed in farms, especially for picking and packing produce. Most of the workers are young, in their twenties and thirties, but a few are older, some even in their sixties. Typically, men and women of all ages work from early morning until 6 p.m. Monday through Saturday, and until noon on Sundays. This pattern of working long hours for a *patrón* is common in the U.S. agricultural sector, as described by Chavira-Prado (1992).

Some middle class Latinos hold contradictory views about people who came to work in services or agriculture. They believe those workers are all “illegal immigrants,” justifying Anglos being tired of “illegal immigrants,” and qualifying them as “*gente extraña*” (“strange people”). After all, they reason, “illegal immigrants” come to live here and are poor; taxpayers have to pay for the services they use. However, they also feel that immigrants come to do the jobs nobody wants, that if immigrants do not take those jobs, nobody will. They feel the immigrants are paid a bad salary and receive no benefits with U.S. employers taking advantage of them. Some people fail to realize that these views

are contradictory. Some believe that if “illegal immigrants” are intelligent enough to enter the U.S. without papers, they should be able to protect their rights. If they are exploited, it is their fault. Perhaps the existence of a marked social class difference and the need of those who consider themselves middle class to look different from the lower income group plays an important role in explaining why middle and upper class Latinos in SWPA express these views.

There is no clear pattern for women who work outside their homes. Women of all social classes and from all countries often work outside the home. However, women are more likely than men to stay at home as homemakers. There are no significant differences by English proficiency or acculturation in the proportions of Latinos who are not in the paid workforce; most of who were women. Some stay at home voluntarily and plan to go back to work when their children are older. Some wanted to continue as homemakers. It is possible that, as found by Erickson (1994) in a study with an ethnographic component about pregnancy prevention in East Los Angeles, some women (and men) believe that motherhood and pregnancy are not compatible with work and school. In SWPA, women of all social classes work when they feel it is necessary, regardless of their traditional beliefs, as found by Chavira-Prado (1992) among Mexican migrant workers in Southern Illinois. However, I do not have enough data to explore this issue. Many women combine work and/or studies with raising a family. It is not surprising that among Latinas, taking care of their family was the most important job. Thus women more frequently take lower paying and part-time jobs, as described by Giachello (1996 b). In other places of the U.S., there is evidence that Latino women regard the family as their primary concern, even when they work outside the home (Benmayor et al, 1997). Flores WV (1997 b) explains that women view their joining the picket lines during a cannery strike in Watsonville, California as a way of defending their families.

**Table 23****Latinos who are not in the workforce in southwestern Pennsylvania by sex, English proficiency and acculturation. Weighted estimates and confidence intervals**

|  | Percentage not in<br>the workforce | 95% Confidence<br>interval |
|--|------------------------------------|----------------------------|
| All                                    | 29.4                               | 11.5 – 47.3                |
| Latino men                             | 5.66                               | 0.84 – 10.5                |
| Latinas (Latino women)                 | 47.84                              | 24.0 – 71.7                |
| Latinos with lower English proficiency | 39.5                               | 13.8 – 65.4                |
| Latinos with high English proficiency  | 15.3                               | 11.7 – 26.8                |
| Latinos with lower acculturation       | 22.4                               | 13.7 – 31.0                |
| Latinos with high acculturation        | 37.2                               | 4.9 – 70.0                 |

Weights for probability of selection, non-response, and post-stratification were applied.

***G. Education***

Most Latinos in the SWPA area finish high school, and many have college or even graduate education. However, some have only a few years of primary school and some have real difficulties reading or writing even their signature. Among those surveyed, unadjusted proportions show that, overall, 30% of Latinos in SWPA have less than college education. Adjusted proportions are not shown, because one of the factors data were adjusted for was education. Nationally, Cubans and South Americans are the ones with the most years of formal education, and Mexicans are the ones with the fewest (Hajat, 2000). Survey data show that the income level of Latinos in SWPA did not reflect their years of formal schooling. Almost half of SWPA Latinos had annual family income below \$20,000, but more than three-quarters had education beyond high school. This is compatible with findings of 1990 Census presented on Table 6, (p. 41). In 1990, 79% of Latinos in SWPA had finished high school,

compared to only about 50% at the national level; however, there was no difference in median income, which was between \$15,000 and \$24,999 for Latinos in SWPA and in the U.S., respectively.

**Table 24**

**Educational level of Latinos in southwestern Pennsylvania. Unweighted estimates and confidence intervals**

|  | Percentage with formal education less than college |
|--|--|
| All                                    | 23.8   |
| Latinos with lower English proficiency | 42.6   |
| Latinos with high English proficiency  | 16.3   |
| Latinos with lower acculturation       | 39.0   |
| Latinos with high acculturation        | 16.9   |

Weights were not applied, because education was a factor in the post-stratification weights.

As most Latinos in the U.S. (Benmayor et al, 1997; Furino & Sumaya, 1992; Gonzalez, 2000; Trueba, 1999), Latinos of all social classes in SWPA placed a high value on education. It was seen as the best way to advance in life, economically and socially. Some people appeared to need to affirm their identity as educated members of the middle class and did not want to be confused with having fewer years of formal schooling. For them it was important to let others know that they had studied and that they had a degree, more so if it was a Master’s or Ph.D. There were several examples of this attitude. In the survey, the highest educational level was “college or more.” Frequently, interviewees specifically requested that I wrote, “Master’s degree” by their response. Two musical groups included in their description an overview of the non-musical academic accomplishments of the members of the group. It is mentioned in the literature that upper class Latinos are fond of their titles, but the reason is not mentioned (Castillo, 1996). Perhaps the fact that income is not

high for most Latinos, regardless of educational level, made having a degree the only way to feel one's social status is affirmed.

All Latinos in SWPA, especially those with few years of formal schooling, want their children to get more education than they did and are willing to make sacrifices to achieve that goal. Informants reported to me that they were concerned about their children attending school and later, a higher education institution. They want a better future for themselves and their families; they save money for this purpose and send at least one child to college. This is similar to what has been described about Latinos in the U.S. (Furino & Sumaya, 1992; Gonzalez, 2000; Trueba, 1999). I met some people who had little formal schooling and who worked, in some cases two jobs, as they were trying to advance through education. José worked in a service job, and spent all his afternoon breaks in the library, studying to take his General Educational Development test (GED). He aspired to go to college. Luz felt she could set an example for her children. If she could get an education while working and taking care of the family, her children would value education more and believe it to be attainable.

Education means more than academic instruction for most SWPA Latinos. They want their children to learn values and customs of their culture, though they are educated in the U.S. For this reason, Latinos, –rich and poor, from Mexico, Argentina, Cuba, Peru, Puerto Rico and other countries, – want their children to experience living in their country of origin. Often, they take the children to Latin America; some even send them to attend school there for a while. For the same reason, they organize celebrations of key cultural events and practiced dances or music. For example, the custom of celebrating *Posadas* is common to both poor and affluent Mexicans at Christmas time. I attended part of that celebration among agricultural workers in the mobile home of one of the families. Mexican families living in an upper class suburb of Pittsburgh would get together to celebrate the *Posadas* in very much the same way, but with more resources, as an interviewee narrated to me. In both cases, the people involved consider it to be important that their children learn about their traditions. This concern about educating children in Latino values and the practice of sending them back to “learn” them is also reported by other

researchers, such as Gonzalez (2000) and Trueba (1999). According to Trueba, this type of education is the responsibility of mothers, who organize cultural events, network with one another, provide emotional support, and arrange that their children spend long periods of time with relatives back home to “learn the culture.” In that way, parents believe, children can acquire a sophisticated education in the U.S. and be at the same time kept “safe,” thanks to the values of their ancestors (Trueba, 1999).

### ***H. Language***

Adults who were first generation immigrants spoke more in Spanish than in English. Their children, after spending some time here, spoke more in English than in Spanish. Families living close to other Latinos have some difficulty teaching English to their children. Those who are more scattered, as is the case of middle class professionals, have difficulty getting their children to speak Spanish. People’s ability to speak both languages at the same time varied. Some, who had lived mainly among Anglos, tended to forget some Spanish and had a decreased Spanish vocabulary. A few, who migrated as adults and had been here 5, 10, 15 and even 20 years, could not maintain a conversation in English. Some Latino SWPA residents that were raised in the U.S. did not speak Spanish because it was forbidden at their homes. They were pressured to assimilate into mainstream U.S. culture. Today, they wished they had learned the language, and they encourage their children to learn it.

According to Schur and Albers (1996), at the national level, Cubans more frequently speak Spanish only (30%) and least frequently speak English only. “Others” and Mexicans are the ones who more frequently speak English only (43% and 38%, respectively); the proportions of the same groups that speak Spanish only are 20% and 23%, respectively, pointing to a more bilingual population. Marin (1989) concluded that, nationally, 25% of Latinos do not speak English, 60% prefer to speak Spanish, and 15% prefer to speak English. Keefe (1992) points to a relationship between race and language, as darker skinned Chicanos tend to speak more in Spanish than lighter skinned ones. I did not gather data on this specific issue.

Many Latino people in SWPA tried to preserve Spanish in its “pure” form. Actually, it is difficult to know exactly what constitutes “pure” Spanish. Often times the same words have different meanings in different countries; sometimes even these meanings are contradictory. Therefore, it was understandable that two Latinos in SWPA had to translate some words into English first, to set the meanings straight. Many people switched between languages in the same conversation and even in the same sentence. The degree of “language switching” varied from the very mild to cases in which there was a complete mix. All these may be considered variants of *Spanglish*. *Spanglish* is the mix of English and Spanish, as described by Stavans (1995) and Stephens (2000). In practice, most Latinos in SWPA speak Spanish mixed with at least some English or *Spanglish* words. There is evidence that this is also what happens at the national level. Hispanics who write literature, do so in Spanish, English, or even in Spanglish (Stavans, 1995; Stephens, 2000). “Code switching” is more than just translating. Stephens (2000) argues that *Spanglish* is the most resonating ethno-cultural symbol resulting from this interaction of cultures.

For many Latinos in the U.S., as for many informants in SWPA, the language spoken has political meaning. Many expressed the belief that they have to learn English, as it is the official language of the U.S. and newcomers need to adapt to their host country. Others told me that they want to be able to speak their own language. In the U.S., some think that Spanish is an “oral language,” good for family and intimate matters and English is a more “public” language, suitable for official business and academia (Gutfreund, 1990; Howard, 1983; Rosaldo, 1997). Rodríguez (cited by Rosaldo, 1997) believes that to continue using Spanish is to contribute to internalized oppression. Others, such as Gonzalez (2000), believe that Latinos have the right to preserve their language and the host country should offer ways to use Spanish for official purposes. Some argue that their families were in the U.S. before it was called “United States,” and they spoke Spanish then as they do now. For Silvestrini (1997) and Trueba (1999), language is a form of resistance, opposing the mainstream view of bilingual education, which sees language as a “problem” or handicap of Latinos. Even benevolent educators tend to believe that once Latinos learn the language and culture of the United States, this is, when their

cultural problem is fixed and their educational problems will also be fixed. Then, immigrants may become a normal part of American society.

For Fox (1996), language is the main common identifier among Latinos and thus has to be used as a source of pride. It is common to read that Hispanics hear from Anglos that they have to speak English all the time, now that they are in “America,” as mentioned by Gonzalez (2000) and Stavans (1995). It is common to hear similar stories from Latinos in SWPA, and has been part of my own experience in the U.S.

It will be shown later how, in a health care environment, language proficiency and language preference are not only related to understanding the provider, but also have implications for diagnosis and treatment, as pointed out by Fabrega (1990) and Guttfreund (1990).

### ***I. Religion***

There are few religious congregations in SWPA specifically for Latinos. The largest one is a Catholic congregation. There used to be no regular Spanish-language Catholic service in SWPA. Those who wanted to attend a Catholic church joined American parishes. Then, 20 to 25 years ago, an Ecuadorian priest, Father Romero, started offering a Sunday service in Spanish. Fr. Romero had come here to study at a local university and stayed in the area. The Catholic community was fairly small, and its members all knew each other. It was a homogeneous, well-educated group; many were members of the *Club Español*, of which Fr. Romero was twice president.

In the mid 1990s, Fr. Romero held mass every Sunday at a small chapel in Central Catholic High School. Attendance varied between 20 to 40 people. During 1996, Fr. Bill, an American priest studying at the University of Pittsburgh, visited the mass often. After Fr. Romero died, Fr. Bill continued the weekly mass. The congregation was increasing in size, perhaps due to demographic pressure, or possibly as a result of Fr. Bill's easy style. Soon the chapel was too small for the services, and the mass moved to a larger chapel at the Cardinal Dearden Memorial Center in Oakland, a move that Fr. Romero had always avoided. The community continued growing and became more diverse.

Every Sunday, some 90 adults attended mass, from many different countries and with varied educational and economic backgrounds. Attendance was noticeably greater in the winter than in the summer, as quite a few people took advantage of their children's school vacations to travel back to their country of origin.

In mid-1999, Fr. Bill left for Chile. In August, Fr. Joaquín, a Franciscan originally from McKeesport, arrived from Wisconsin. He speaks perfect Spanish, as did Fr. Bill. The community continued to grow. Fr. Joaquín added, for the first time in this community, non-Sunday masses, such as those for the Day of the Dead, the Immaculate Conception, the *Virgen de Guadalupe*, Christmas, New Year, Ash Wednesday, Thursday, Friday and Saturday before Easter. He also initiated contact with other groups of Latinos, such as the ones who work in agriculture in Washington County. In 2000, some 100 adults attended mass every week; sometimes the number reached 130. Around 50 of the people who attended mass did so every week; the rest did not attend every Sunday. There was usually more than one baptism each month; once there were three baptisms in the same day. The growth of the congregation had stirred up some conflicts based on social class among community members and Latinos in SWPA. Some perceived the church to be ruled by affluent people who would not let the poorer segments of the congregation take an active part in the service. Others viewed the church group to be too heterogeneous, including too many people who were “not like [them];” they stopped attending as a result.

Soon, this chapel was also too small, and the community would move to St. Regis/St. Hyacinth Parish in Oakland, following Fr. Joaquín’s initiative. Most people were in favor of moving, because it would allow more people to attend mass, and it would give the community a more “official” place in the dioceses. However, some were opposed to the move, as they felt becoming part of a parish, even when enrollment was voluntary, would scare those who had an uncertain immigration status. Others disliked the money collection system of U.S. parishes, especially the use of envelopes labeled with donor’s names; they felt all donations should be anonymous. Still others disliked the current social diversification of the community and feared that moving to a bigger place would allow “just anybody” to come. Again, conflicts based on class surfaced.

At the time the data collection ended, mass usually started 15 minutes late, and some people continued entering well after it had begun. There were extra chairs, but not enough, and several people remained standing. Sometimes they listened to the sermon sitting on the floor. Families brought their children. Infants were in strollers or carriers, or were held by parents or other adults who “borrowed” them. Preschoolers walked around, crawled, and sometimes ran. They played with dolls and robots and were noisy. One to three people played the guitar; usually a woman played the *bombo* (a drum) and sometimes others played the violin or the *charango*. Music was informal and everybody sang. At the time of “peace giving” most people walked around greeting other church members. Some took the opportunity to chat. At the end, there were some announcements about social events taking place in the community, music presentations, available health services, and the like. After mass there were donuts every other week, brought by a volunteer and served in another room of the same building. Parishioners stayed for about an hour. Some people rarely stayed, such as a group of several young men, some of whom were Mexican and worked in restaurants. When there were no donuts, people stayed after mass for only about 30 minutes. Leaving was never easy; everybody took the opportunity to catch up with everybody else. People seemed to like Fr. Joaquín’s style, especially his meaningful sermons filled with religious teachings, although some complained his mass was too long. The community showed its support when Fr. Joaquín’s mother died; some thirty Latinos from the congregation attended the funeral service.

Abel, a local restaurant owner, told me that recently masses began to be offered at his restaurant late on Sunday evening. This time schedule made it easier for restaurant workers to attend. A U.S. priest and friend of Abel’s, officiated and approximately 20 people attended each week. This religious arrangement tended to the need of a particular population and was entirely unrelated to the university and professional Latino groups. It was truly a grassroots initiative; people saw a need in their community and found the means to address it.

It should not be thought that non-Catholic groups were unimportant. While it might be true that the Catholic group was the largest one, another

factor is that I was not able to obtain as much information from the other groups. A U.S. Pentecostal pastor mentioned a Puerto Rican Pentecostal pastor he knew more than ten years ago. At my request, he located him again, but attempts to meet him failed a couple of times. Finally, we spoke on the phone and then I visited him twice. He lived in an inner city section of Pittsburgh, where some Pentecostal Latinos, mainly of Caribbean origin, and older than 50, lived nearby. They worshipped together with an American congregation, but they also held smaller services and discussions in Spanish at the home of their Puerto Rican pastor. At one of my visits, the pastor played religious songs and members of his group sang with him. We also prayed, but this was not a formal service; rather, it was part of the social activities before dinner.

Several people told me that a Lutheran church just outside Pittsburgh held a weekly service in Spanish. Two pastors from a different church were in charge of it. I spoke with one of them, and he connected me with one of the church members. Attendance was mostly made up of Cubans. At some point, there were about 30 members, but the number had decreased as many Cubans left for Florida. Attempts to visit the service failed; due to low attendance, sometimes there was no service. However, their "list" was in my sampling frame and some members of their group were surveyed.

There was a sizable group of Latino Jehovah's witnesses. One informant said that they held a weekly service in Spanish in East Liberty, attended by 68 people, many of whom came from Butler County. Another informant put the number at 120. I have seen Latino Jehovah's witnesses visiting the homes of Latinos. They came with their cars, parked, rang the bell of houses with Spanish speaking people, and left their publication, *Atalaya* (Watchtower). However, they did not visit my home during the data collection period, and I could not meet with them. The informant who attended their service sporadically had too many health problems, as she developed a chronic disease that limited her ability to go around. This made it impossible for us to attend together.

An American Mennonite pastor who spoke Spanish and had lived in Honduras for some time, occasionally offered bible study sessions in Spanish. I have known him for quite some time, as we live in the same area of the city. He

said that one or two families have attended the bible study sessions with some frequency, but that it is not a formal congregation of Latinos.

According to one informant, there was a group of the *Asambleas de Dios* (Assembly of God) in Carrick, headed by an Argentinean, but I have not been able to verify this information. It might be the same group mentioned by Patrick (1973) as based in the North Side. There might be other small religious groups throughout the area. Many Latinos with whom I spoke attend church sporadically or only on high holidays. Many attend American churches, and many others did not attend any church at all. Additionally, some of those who belonged to one church might attend other churches for certain occasions. Some might change their religion upon marriage. I met two men who became Jewish and one that became Lutheran for that reason. Others felt that religion was immutable and they would never marry outside their faith. However, though there was variety in religiosity, most Latinos said they respected their religion in some way, even when they did not comply with their obligations regularly. Most of the latter said they professed Catholicism.

It was no surprise that most Latinos appeared to be Roman Catholic. Giachello (1996 b) reports that at the national level, 85% belong to this religion. However, other groups have been growing in numbers. Nationally, Puerto Ricans are more frequently Protestant, but many Protestant churches in the West have gained adherents among Mexicans.

Religious services in Spanish in SWPA tend to both the spiritual and social needs of Latinos. This was also noticed by Wilson (1998) in a class project on the History of Latinos in Pittsburgh. Many people I met during the course of my study attended the Catholic mass with the intention of meeting other Latinos and feeling more “connected” to *nuestra gente* (our people). Some people did not attend mass, but came after the service to meet with friends. People networked and talked about a variety of issues, including child care, food, and bus rides. They exchanged information about how to do things in this area and organized community picnics or other smaller group meetings. Most Latinos preferred to attend religious services in Spanish because they understood them better, because they felt the other parishioners were like them, because they got connected with other church members, or because they felt discriminated in

American churches. In an extreme example of the latter, a woman said that she used to attend a Catholic church in a European American area where her husband's family lived. The parishioners there looked down on her because she was dark skinned and did not allow her to sing in the choir or to participate in organizing events for the church. Later, she became a Mormon and at the time I met her she attended a church where people were "from everywhere," and she did not feel other church members discriminated her. Sometimes, however, she wanted to listen to some Spanish and to see other Latinos. Then, she attended the Jehovah's witnesses' service.

### ***J. Entertainment and Food***

SWPA Latinos like to watch TV in Spanish, and many subscribed to satellite TV just to watch the Latino channels. They watched *telenovelas* (soap operas) soccer, the news, and *Don Francisco*. They preferred Latino networks because they gave more information about Latin America, aired "*our music*," they were not regarded as obscene (this could be really contested), and the people on the screen looked like "*us*." For some, especially those with fewer years of formal schooling, getting TV in Spanish was of paramount importance. It was a necessity and when they were at home, they had a Spanish channel on, as though it were background music. In contrast, some professionals who would like to have satellite TV did not buy it, because they considered it too expensive. Perhaps professionals could relate more to TV in English and understood the language better. For them, Spanish TV was not as necessary to feel connected and informed, and their "cost-benefit analysis" did not guarantee such an expense. Some Latinos preferred to watch TV and listen to the radio in English, because they believed they would learn more English that way. Some who were bilingual preferred to watch TV programs in their original language, (Spanish or English), because they believed translations were never as good as the "real thing." There is only one radio program in Spanish, a weekly one-hour space called *Revista Radial Latinoamericana*. (Latin American Radio Magazine) It offers news, music, interviews and social service announcements. Lately, the program includes an expanded version of the sports section; it is broadcast in

Portuguese at least once a month. However, it is difficult to say how large an audience this program reaches.

A few clubs or restaurants offer Latino dance music in the Pittsburgh area. Since many patrons are Anglos, the rhythms played by clubs are mostly salsa and *merengue*, currently in vogue in the U.S. Many young and some middle-aged Latinos go to these places, especially on weekends. They might go in groups or with a date, but this is not necessary; quite a few people go alone. A few enthusiasts drive as much as 45 minutes every weekend just for an evening of dancing in Pittsburgh. Clubs charge a flat fee at the door (usually \$5), and patrons buy their own drinks. The clubs are generally safe, but people told me that sometimes a group of men might start a fight outside the restaurant. Not everybody likes this music. Some of the “older” crowd do not go because it is “too noisy.” Others are tired of salsa and *merengue* and would prefer music from their countries, such as *corridos*, *quebraditas*, *cumbias* or *valses*.

Latinos of all social classes like to attend parties, private or public. Those who have children tend to take them along. Parties run late, and there is often no set end time. Almost always there is dancing and many times there is singing. Children might join in the dancing. The feeling is of a disorganized meeting, where many people talk at the same time, usually in Spanish and *SpanGLISH*, but also English and sometimes Portuguese. Most social gatherings involve people from several regions. However, there were more limited gatherings, such as Argentineans’ *asados* (barbecues), for example. A few people preferred to meet with their U.S. and Latino friends separately, believing the groups did not mix well.

Food served at gatherings is central to the celebration and is almost always typical of one or more countries, depending on the audience and the origin of those preparing the food. Often times, people bring food that is typical of their own countries, and share it. Food, especially ethnic food, is a common theme of conversation among Latinos. People pass along tips about the best places to get quality (and inexpensive) produce to prepare these meals. Some people go to great lengths to get the food items they needed. Many invested time and money in procuring the required ingredients, even when their income was

low. Some might bring some food back when they traveled to their countries. Some organized special trips to Cleveland, Columbus, Erie, New Jersey, or Washington, D.C. to buy groceries. Latinos living in small towns in SWPA tended to come to Pittsburgh's Strip District or go to Erie for their special groceries. Some even had food items shipped by mail. Food was such a big deal that many people showed disappointment when the 1999 Latin American and Caribbean Festival sponsored by the University of Pittsburgh excluded it. For many, that had been the main reason to attend the festival: to have Latin American food while chatting with friends. The importance of food, culture and entertainment for Latinos from many origins in the U.S. is not something new. Food and music accompany most gatherings that are expected to be socially meaningful for Latinos everywhere in the U.S. (Flores WV, 1997a; Gonzalez, 2000; Silvestrini, 1997; Trueba, 1999). Of course, this might be true of any other ethnic groups in the U.S. and elsewhere.

### ***K. General Beliefs, Concepts and Views***

#### 1. About the U.S.

Several Latinos have preconceived ideas about the U.S. Perhaps one of the most common ones is that sexual liberties are exaggerated here. This is reflected in the desire of most Latino parents that their children not leave their home when they reach adulthood. They view the U.S. custom of grown children moving out as being intrinsically bad, leading to evil and degeneration. Many believe that children here are too loose. In their country, there was more control; everybody in their community took care of them or would tell the parents if they saw the children acting inappropriately. One woman believed that Latino parents have to teach values to their daughters, so that they do not end up as "*putitas*" ("little whores"). Some view these perceived extreme sexual liberties as encouraged by schools.

Along the same lines, some Latinos, especially males and older people, are prone to make homophobic remarks when around other Latinos. They disapprove of men wearing earrings and other "unmanly" accessories and equate this practice with homosexuality. These attitudes are not surprising,

because an intense rejection of homosexuals, especially by Latino males, has been reported in the literature (Marin, 1989). However, many of the younger Latinos in SWPA, who considered themselves straight men, wore earrings and other jewelry objects.

Other preconceived ideas included stereotypes of men and unsubstantiated fears. For example, a woman mentioned that American men were not good to marry, they were “*así*” (that way), did not understand us, did not eat what one cooked, and liked only canned food. Another preconceived idea was concerned with the possibility of somebody kidnapping children to take away their organs for transplants.

## 2. Luck and Fate

Some SWPA Latinos believed in luck and fate. Some related it to religion and wore faith-related amulets, such as rosaries, around their necks, or hanging from the rear view mirror of their cars. Others had more secular ideas of luck. For example, one interviewee said that back in his country he used to drive a bus between two cities. There was a young woman who traveled his route frequently. Every time she went on the bus, they had at least one flat tire. The lady knew she brought bad luck and told my interviewee that. Therefore, as soon as he saw her boarding, he would plan to pick up extra spare tires for the trip. I thanked my interviewee for his help, and told him his was the first survey I filled out. He said that in that case, my work would go all right, because he brought luck to everything in which he participated.

## 3. Politics

Politically, Latinos in SWPA are diverse. They ranged from the most conservative to the most radical. In spite of this, many see U.S. politics as unimportant. They care more about what happens in Latin America; politics rarely created divisions between them in the U.S. However, in a few cases, perhaps the most clear would be the Cuban case, talking about politics could stir passions and the discussion would be never-ending.

## **L. Discrimination**

Being Hispanic in SWPA, as in the rest of the U.S., is sometimes not easy. Having a Spanish accent, having dark skin, having a strange last name, and/or being originally from Latin America could all trigger a discriminatory response. Commonly SWPA Latinos perceive that as soon as people hear their Spanish accent, they start treating them as if they are somehow not intelligent beings. They say that Anglos tend to over explain and speak very loud to be understood. Another common way Anglos react to accent, according to many Latinos in SWPA, is to act as if they did not understand what the Latino/a said, even when they did understand. Often, an unfriendly face and/or a demeaning look accompany this reaction.

Some informants feel that Anglos discriminate against dark-skinned Latinos, –especially brown-skinned Latinos– more quickly than against light skinned ones because they are immediately identified as immigrants, (perhaps illegal immigrants), even when they might be U.S.-born. In addition to discrimination based on being an outsider, they face discrimination based on being dark. Light-skinned Latinos also face problems. They look white, and when they do not have an accent they are not believed to be Latinos. As children, for example, they might be excluded from both Latino and Anglo groups in school.

Several people reported that some Anglos assume all Latinos are poor and uneducated. For example, all Mexicans were believed to work as migrant agricultural workers, dishwashers or nannies. “*Creen que todos cruzamos el Río Grande y no somos educados*” (“They believe we all crossed the Rio Grande and we are not educated”). Even a well-intended compliment might have discriminatory content. For example, a woman was told at school that her child had very good grades, even though he was born in X country.

Not all Anglos discriminated against Latinos, but many did. All the types of discrimination found in SWPA (i.e., skin color, accent, country of origin, different customs) have been described elsewhere (Gonzalez, 2000; Trueba, 1999). Many of those reactions are based on stereotypical images of Hispanics. In some cases, Latino culture is considered odd and constitutes the reason for

discrimination. Anglo perspectives impose a cultural paradigm, and other world views are not accepted (Brink, 1994; Fabrega, 1990).

Latinos in SWPA said that they reacted to these stereotypes in several ways. Many were confused at first; later, they became frustrated and angry. As they learned more English and understood what happened, some said that being assertive was the best response. They recommended that Hispanics act confidently, as “if they owned the place”, as “the boss.” Being polite and trying to carry a pleasant encounter does not work when facing discrimination, because Anglos think you consider yourself to be inferior to them, they said. Others try to prove the stereotypes wrong. This is especially true for educated Latinos. Unfortunately, though they tried to prove they did not conform to stereotypes, they themselves stereotyped other Latinos and discriminated against them, based on socioeconomic status. We cannot overlook discrimination among Latinos themselves occurs. Most often, this is based on class, but sometimes it is based on race and national origin. Many Latinos also discriminate against Anglos and consider some of their customs odd and incomprehensible.

As seen above, there was discrimination by Americans against Latinos. Interestingly, in SWPA, people of middle class appear to complain more about discrimination, than those with lower incomes. According to Keefe (1992), feelings of being discriminated against are usually based on overtly expressed attitudes, such as being called names or treated rudely by an Anglo person. Forms of discrimination that have worse consequences, but are subtler, are felt less. People might not realize that their employment situation -low salary, no health benefits, and lack of promotion - might be in part discriminatory. Perhaps middle class people in SWPA might notice discrimination more often for two reasons: 1) they expect to be treated better and, 2) they are usually in contact with more Anglos than poorer Latinos; the latter tend to work long hours, mainly among fellow Latinos.

### ***M. Organizations and Groups***

There are few organizations of Latinos in SWPA; most are cultural. Most are informal or operating in an informal way, as Silvestrini (1997) mentions is frequently the case among Latinos in the U.S. Nelson and Tienda (1997) believe that class is the main reason why Latinos identify as a group. That is, those who are poor and have few years of schooling identify as a group. However, Flores RR (1997) argues that in the U.S., class identification has not developed to the extent that it conditions everyday practice. Instead, cultural and social affiliations have been the site of political and group formation activity. This is why, Flores explains, cultural practices that are meaningful to the group are needed for social consciousness to rise and to set the stage for collective action. It is a response to the commodification of culture as exotic tourist good that can be purchased. It is common for Latinos to form cultural organizations to show their customs and folklore, especially dances and music. Gonzalez (2000) and Silvestrini (1997) argue that later, often because of discrimination, or what Jones-Correa and Leal (1996) call a “common material need,” those organizations tend to develop into social service agencies or political groups. Trueba (1999) even says that cultural groups “naturally” turn to political action in favor of the ethnic group. This usually happens when there is a need to defend the community's rights or to improve living conditions.

However, Latinos have not organized for collective action in favor of their ethnic group in SWPA. Cultural organizations continue to be cultural organizations, even after ten or twenty years. Why? Most Latinos in SWPA have been middle class, and their immediate needs have been for the most part satisfied. Their experience with “common material need” has been more limited, and their class consciousness has been low. The activities of cultural groups in SWPA have been closer to the commodity way of defining these actions, as they have been carried out by mostly middle class people. What about those who were poorer and did experience problems? Those who were arriving in more numbers today? Here, geography has played a role. Since our community is still small and scattered, organizing for political action is difficult and has not happened yet.

### 1. Club Español

The *Club Español* was perhaps the oldest organized group in the Pittsburgh area. It was started by a group of Anglos who appreciated the Spanish language. This explains the peculiar name, which translates as “Club from Spain,” rather than as intended, “Club of Spanish.” As some Latin Americans arrived in the area, they joined the *Club Español*. Most were professionals who devoted their free time to preparing cultural presentations, such as folkloric dances, lectures, painting shows, and typical costume shows. They celebrated Columbus Day with a formal dinner and dance and held other social functions. They participated with a presentation and a food booth in festivals, such as the Latin American and Caribbean Folk Festival. All work was voluntary, and this led to some members of the group leaving to pursue professions in music and dance. Later, problems between people of different national groups arose. Some Hispanics in the area felt the problems were related to class discrimination. They resented the upper class orientation they perceived the club to have. Due to conflicts, several groups of people left the club. One of those groups created the Latin American Cultural Union in 1986. By 1998, the *Club Español* was inactive, for the most part. There were rumors that there were persons who were trying to revitalize it, but I have not been able to confirm this.

### 2. Latin American Cultural Union (LACU)

The Latin American Cultural Union was founded in 1986. It was incorporated as a non-profit organization with the mission of cultivating Latin American ethnic identity and disseminating Latin American culture in the United States. Internal conflicts have been a problem in several instances, but the organization is still thriving. It has approximately 200 members from many different countries. Most are middle class people, but there are a few exceptions. Like the *Club Español*, LACU operated on a volunteer basis. Its members prepare cultural presentations for festivals, organize benefit parties and concerts, and are hired to dance at some events. The money raised pays for other LACU events, such as the Christmas party, the annual picnic, and the

Mothers' Day dinner, as well as for maintenance of existing costumes and purchase of new costumes. LACU also offers activities for families. Some activities tried to include a group more representative of the current demographic makeup of the area's Latino community. However, efforts to reach such groups met with mixed results.

### 3. *Coro Latinoamericano*

In 1997, a Venezuelan musician founded the *Coro Latinoamericano* (Latin American Choir), to create a space where Latin American music could be enjoyed at a more "*culto*" (cultivated) level. At first, some thirty members, Latin Americans and Anglos, practiced at a church and held small presentations. As time passed, they managed to stage more elaborate presentations, some including other musical groups. They changed directors a couple of times, lost some members and added new ones, but they continue working. They usually introduce themselves as "a group of professionals, researchers and students devoted to unite Latin Americans through choral music".

### 4. *Latinet*

A few years ago a group of students at the University of Pittsburgh created an e-mail distribution list for Latino students to communicate with each other, called *latinnet*. It was redefined later to include all Latinos in the area who wanted to communicate in this way, as well as non-Latinos interested in Latino affairs. It is used to share information about events and jobs, as well as comments about news of Latin America and the U.S. It is even used for moving sales. Membership in *latinnet* is variable; some people sign up for a period of time, then unsubscribe. After a period of time, they might subscribe again. The number of members oscillates, but it is usually around 100 or 150 people, most of them based in SWPA. Many, but not all, of *latinnet* subscribers are Latinos. Members find out about the list through word of mouth, and the list is not generally advertised.

## 5. Other groups

The Hispanic Chamber of Commerce has an office in downtown Pittsburgh. They organize monthly meetings and try to reach Latino business owners. However, many of its members are non-Latinos. There are smaller and more informal groups in the area, including several women's groups that meet periodically to share experiences and socialize. For example, there was a group of friends in Greensburg, that called themselves the *cotorras* (parrots). There is also a group of Mexican women that get together in a suburb of Pittsburgh to exercise and chat. Other groups do not necessarily meet, but constitute informally organized networks of information, sometimes including persons from the same country of origin, such as the case of Argentineans and Colombians in SWPA. Other organizations might exist, than those mentioned here. They may be smaller or might just not involve the people I had the opportunity to meet during this research.

## 6. Musical groups

Perhaps the oldest Latino musical group in the Pittsburgh area was "*Guaracha*," a band led by Miguel Sagué. Other bands included "*Orquesta Tropical*" (Tropical Orchestra), "*Sabor Latino*" (Latino Flavor), and "Latin Impulse". There was a group called "*Musuhallpa*" (Beautiful Land, in Quechua) that played Andean music and another called "*Cuarteto Latinoamericano*" (Latin American Quartet), which played chamber music. Several clubs offered salsa instruction, and one group met privately to learn and enjoy tango dancing. Local Latino bands perform at least weekly in the area and offer entertainment to the community. They are also a source of informal work for some. Some of the bands had relationships with other organizations and volunteered their music in fundraising events, for example to collect money for Hurricane Mitch victims.

## 7. Center for Latin American Studies (CLAS)

The Center for Latin American Studies (CLAS) at the University of Pittsburgh is not an organization of Latinos. However, it is an integral part of the cultural life in Pittsburgh. Many people who lived in the area had been

students of the center, and it offered conferences and sponsored different cultural and academic events. For the common Latino or Latin American in SWPA, perhaps CLAS was best known as the sponsor and organizer of the Latin American and Caribbean Folk Festival. This annual event has taken place for more than a decade. It used to include musical and dance presentations and booths to sell crafts and ethnic food. A variety of individuals and organizations would be responsible for presentations and booths. People would eat, chat, listen and dance. At the end, an open dance would close the night. The festival attracted many residents of Pittsburgh and SWPA. Some came from as far away as Erie or Harrisburg just for the festival. For many, this was the one day in the year they had to talk with and meet other Latinos, while enjoying Latin American food.

In recent years, in part due to problems finding enough space for the growing crowd, the festival changed locations and dates several times. In 1999, the CLAS decided to eliminate the booths that sold food and crafts. In the months preceding the festival, almost every Latino in town was talking about the changes. Most people voiced disagreement with the decision to eliminate the booths. Some already had a mental list of what they wanted to eat. Some had a list of what they were going to cook and sell. The most upset were those who had been cooking for and/or eating at this Festival for many years. Just music and dances was not enough, was the opinion I heard everyone voice. Even some people who had never attended the event and those that were relatively new to town were upset, because they were expecting this event that “everybody” had told them was a great one. Apparently, the community had taken ownership of the festival and thought it was part of their community life, more than CLAS leaders realized. For CLAS, the commitment to outreach was to bring Latin American culture to the local community and the students of the CLAS, not specifically to serve the needs of the Latino community of Pittsburgh or SWPA. Not surprisingly, the 1999 festival had a smaller attendance than the usual one. As a result, there have been many talks about preparing another festival that could offer food and crafts (especially food). However, much work is needed and funds were hard to come by. So far, nothing clear has transpired. Such a festival is a difficult task for a loosely organized community.

In 2000, the CLAS festival once again included food and crafts. This was a change that community members welcomed.

### 8. "Sacred places"

In Latino communities there exist what Rosaldo and Flores (1997) call "sacred places." These are places that serve as safe havens, where people feel comfortable, are able to discuss their problems, and have a sense of their culture. A "sacred place" might be a mall, church, club, or any other place. In SWPA, the Spanish-language Catholic mass might be one of the few year-round "sacred places." However, gatherings such as the Latin American and Caribbean Folk Festival might qualify as such, even though they happened only once a year. This might be the reason people felt so upset in 1999 when it failed to meet their expectations by not including food. Another "sacred place" might be the restaurant in Oakland that offers mass on Sunday nights. In this place people of lower income meet freely to worship and socialize. For the past two years, many Latinos have been talking about the need for a public place "for all," a "*Centro Latino*" (Latino Center), a physical place to gather. This might indicate that there is a stronger desire to have a more cohesive community, at least in Pittsburgh than there was before.

## ***N. Latino Ethnicity***

### 1. Race and ethnicity: Unclear concepts

Race doesn't have the same meaning for all Hispanics and it is by no means a clear concept (Marin & VanOss Marin, 1991). In the U.S., it is divided into "white" and "black" (Fox, 1996; Gonzalez, 2000). The dichotomy constitutes a problem for Latinos, who are not used to viewing race in that light; for them it has many shades (Romero, 1997). Stavans (1995), a Mexican Jew, says that before he came to the U.S., he did not know the meaning of the terms race and ethnicity. These can also be said of Latinos in SWPA. As far as I could observe, race is an important issue, even when some people are tired of talking about it and being misunderstood. Some children are tired of hearing the question, "What is your race, anyway?" from classmates. Around Census Day 2000,

people talked a great deal about definitions of race and ethnicity. Perhaps the most illustrative example of the different concepts is one that happened at a Census 2000 awareness meeting. Many people complained that *mestizo* (mixed races) was not an option for the race question. Many people felt such a category is needed because Latinos can be of any race, but most commonly are a mixture of two or more races (Fang et al, 1997; Fox, 1996; Gonzalez, 2000). At the meeting, participants were told that they could make up their own *mestizo* category by checking more than one race. However, several people felt this was not an adequate solution. They characterized themselves as *mestizo*, because they were not White, Black, Indian or Asian, and they did not know which or how many races made up their *mestizaje* (mixture).

For Latinos, as for many other groups, social status and race are not separate concepts. The darker people have always been considered to be less valued, according to Oboler (1997) and Rivero (2000). In SWPA, many Latinos try to present themselves as being as White as possible to attain social status. Other Hispanics try to emphasize their Indian or Black heritage making it a source of pride. Flores WV (1997 a) argues that race and class together are central to understanding empowerment. Other than skin color, race has little to do with genetics and tends to be more a social construct. For that reason, Williams et al (1994) feel the term is better used along cultural lines. For Latinos, perhaps the term ethnicity is more appropriate.

## 2. Do labels matter?

Pan-ethnic labels, as defined by Jones-Correa and Leal (1996), are those that refer to a group of people and not to a specific country of origin. This is the case with “Hispanic” and “Latino.” Latinos in SWPA, as in other parts of the U.S., according to Furino and Sumaya (1992), Gonzalez (2000), and Trueba (1999), have mixed feelings about these labels. Frequently informants in SWPA did not know the exact meaning of each label; they often found the terms confusing. Many interviewees asked for a definition of the terms before choosing one. Many embraced both labels. Also, as Benmayor et al (1997) and Cuello (1998) have noted about the U.S. in general, people often identified themselves as Latino and/or Hispanic, but they preferred to be referred to by a national

name, such as Mexican or Venezuelan. Interestingly, this was the case even when the person had been born in the U.S. It was rare for a person born in Latin America to refer to her or himself as American, meaning “from the U.S.”

Some older and more affluent Latinos in SWPA are more likely to accept being called “Hispanic” than “Latino,” because their culture came from Spain, they said. They disliked the term “Latino” because it meant nothing to them, and they perceived it as recently invented. Others preferred to be called “Latino” and definitely disliked the term “Hispanic”; for them, it meant “from Spain,” and they resented the term. It was my impression that the ones who liked the label “Hispanic” were more conservative than the ones who preferred the label “Latino.” These responses reflect those of Hispanics at the national level. Some view “Hispanic” to be a neutral, pan-ethnic label that avoids stereotyping people as part of an underclass. It is preferred by the upwardly mobile, the group Cuello (1998) calls “Huppies” (Hispanic yuppies). Others, such as Marin and VanOss Marin (1991), see “Latino” to be the neutral term inclusive of all Latinos. The term has a connotation of change, and, for many, it implies a struggle for equal opportunity in the United States. According to Cuello (1998) and Thomas (2000), activists, political leaders and academics frequently prefer to use the term “Latino.”

Although this conflict seems to be new, it is not. As early as the 1920s, there was a sizable group of Latinos in New York City, mostly comprised of Spanish and Puerto Rican people. At this time, the more affluent and conservative called themselves “Hispanic” and considered themselves descendants of the “brave race of Conquistadores.” Working class people called themselves “Latinos”; specifically, they referred to the group as “*la comunidad latina*” (“the Latino community”) in a working class periodical, called *Ateneo Obrero* (Thomas, 2000). Whether the positions and views held then are related to those held today is unknown to me, but the values attached to each label now are similar to those attached eighty years ago.

Some Latinos in SWPA rejected both labels, seeing them as synonymous with low education and uncertain immigration status. However, often the very same people who objected to these terms were concerned about having their children learn about the traditions of Latin America (especially music and food),

believing them to be important to their cultural identity. Apparently, they view the existing labels as resulting in prejudice and stigma. Instead of trying to address the stigma, they circumvented the problem by rejecting the label. They tried to create a different perception of the group, one that includes traditions, but distances itself from lower class or illegal immigrants.

Studying a political survey conducted among Puerto Rican, Mexican and Cuban Latinos as early as 1979, Jones-Correa and Leal (1996) found that most Latinos identify themselves by using a national term, but as many as 41% also use a pan-ethnic label. People of all incomes use a pan-ethnic label with the same frequency, but second and third generation Latinos tend to use it more frequently. Even though pan-ethnic labels are not related to political ideology, they are used more frequently by those who tend to be more actively involved in politics (i.e., to vote), regardless of political affiliation. So, the use of a pan-ethnic label is not purely cultural or instrumental. It is a complex phenomenon, and Jones-Correa and Leal's study indicates that people may have real attachments to a constructed identity. People need a pan-ethnic term, and they use the ones at hand to refer to a group that, even if not well-defined, they recognize to exist in this country. According to Marin and VanOss Marin (1991), the term Hispanic is a label of convenience; the same can be said of the term "Latino."

As Keefe (1992) suggests, gauging cultural identification by asking respondent whether they identify with particular labels is misleading; the Chicanos she studied identified with a group, but did not agree on what label was better. In SWPA, when I requested interviews, clearly saying that I needed to talk to Hispanic/Latinos about health care, people answered that, yes, they could help me. Implicitly, they accepted being Hispanic/Latino. When asked specifically about what label they preferred, however, many would criticize and reject both labels. In other words, the existing labels were used because they filled a practical purpose, but not because the terms themselves were deemed particularly acceptable. This points to the existence of some ethnic identification.

## ***O. Cultural identification: a happy family?***

Ethnicity may be defined as “the collection of group-specific behaviors that are mediated by those social values that are the characteristic of a given group” (Marin & VanOss Marin, 1991). The Bureau of Primary Health Care (BPHC) a division of the U.S. Department of Health and Human Services, (1996) defines cultural group as “a group of people who consciously or unconsciously share identifiable values, norms, symbols, and some ways of living that are repeated and transmitted from one generation to another.”

According to Fox (1996), all people need to belong to a group. The sense of mutual recognition among Latinos has been mentioned in the literature, but exactly what characteristics are necessary for that to exist is less clear. Keefe studied the meaning of ethnic identification among Chicanos and Appalachians. She admits that is not easy to tell who is Latino and who is not without asking the person directly. However, she argues that self-identification is a key part of ethnicity. There are, Keefe believes, three elements of ethnic identity. The first element is ethnic culture or traditions, including food, celebrations and music. The second is participation in an ethnic network of people. The third and most important element is identification with one’s group versus others. This is the aspect of ethnic identity that really makes the difference. When people perceive themselves to be part of a group, they become part of it. This process usually involves assertion and defense of equal status, and it implies the development of emotional attachment. The Bureau of the Census (1999) is right when it uses self-identification as the gold standard for determining who is a Latino.

Ethnic identity often solidifies in the face of injustice, such as discrimination. The experience of discrimination, as hard and unfair as it is, helps to create a common experience among Latinos (Flores WV, 1997 a; Jones-Correa & Leal, 1996; Keefe, 1992; Nelson & Tienda, 1997; Oboler, 1997; Trueba, 1999). People feel validated upon hearing that others have faced the same problems. Additionally, it serves to level the ground: regardless of social status, most Latinos experience some sort of discrimination. Discrimination creates a bond by extension, too. For example, undocumented workers are considered “illegal aliens.” Therefore, every Latino is considered suspicious of

being an “illegal alien” (Flores WV, 1997 a; Gonzalez, 2000; Hayes-Bautista, 1980; Rosaldo & Flores, 1997; Trueba, 1999). “Illegal aliens” are immediately regarded as criminals who break the law and do not pay taxes. The whole group is threatened by these ideas. A response to discrimination is to challenge the system, which aids in the development of ethnic consciousness. Rocco (1997) observed this sense of support among Latino workers in California. They tended to stand up for each other at work and claim their rights. This happened not out of a sense of class-consciousness, but because they and their fellow workers were Latinos. Perhaps the demands they were making related to ethnicity, such as having the right to listen to loud Latino music while at work. Nelson and Tienda say that “when the ethnic experience includes rejection, discrimination and oppression, the elaboration of ethnic ties provides a ready system of support groups distinguishable by race, national origin or language” (1997, p.9).

Hispanics in SWPA appreciate and seek relationships with one another. They tend to compare their language and habits with the goal of identifying commonalties. They build networks of friends and fictive kin and organize their lives around them. In many cases, Latinos in SWPA might be active in more than one group (i.e., LACU and the Catholic congregation). This is reflected in the system of communication that exists. Some organizations have some conflicts, but are able to work together on a practical level. Usually, an organization uses all available groups to convey its message. For example, an event organized by the *Coro Latinoamericano* might be announced via the CLAS electronic bulletin, though the *latinnet* distribution list, during the Catholic mass and at local restaurants. It would be hoped that word-of-mouth would carry the information to the broader community.

Many Latinos in SWPA did not feel comfortable being around Anglos only; they needed to feel a connection with others like them. Even some U.S.-raised Latinos who did not speak Spanish did not identify themselves as mainstream U.S. citizens. They felt they did not fit in any other group, and identified with Latinos due to their heritage. They needed to feel a sense of belonging to a community, even if it was an imagined one. Additionally, many felt they had to be united to survive in the U.S. For many this feeling was

related to shared concepts and experiences regarding family life. For others, a common language was important. For many, the reason for the bond was less clear and surfaced as music and food. One young U.S.-born Mexican with a Spanish surname living in Pittsburgh said that even when he did not do it purposely, all of his friends tended to be Latino. He felt they shared a common perspective: “I know where they are coming from; they know where I am coming from.” This gives him “a sense of security. They don’t assume things...I look white. I get a bunch of crap because of that.” His friends were, according to him, *like him*. Several of his friends were born in the U.S., and their families were from various countries in Latin America.

To this point, we have seen that Latinos in SWPA share traditions, participate in ethnic networks, and identify with each other, although often in limited groups. The formation of a unified group is still a slow process in SWPA, possibly resulting from the characteristics of a small and scattered population. According to Zsembik and Beeghley (1996), ethnic ties and identity are more likely to develop when there is continuous immigration, when there are large numbers of immigrants, and when there is geographical proximity.

#### ***P. Are SWPA Latinos still in Latin America?***

Is there group self-identification? Among some groups, there is a constant longing for their land of origin. Some felt that they were here only temporarily, even though they may have lived in the U.S. for as long as 40 or 50 years. There were others who felt they had “moved” to the U.S. and considered this country to be the place where they would live permanently. First generation immigrants I spoke with always dreamt of going back to their land. Interestingly, several second generation Latinos also dreamt of retiring to Latin America. However, just 11.93% (95% confidence interval 6.8-17.1%) of Latinos surveyed planned to stay in the U.S. for less than 5 years, and 61.1% planned to stay indefinitely (95% confidence interval 45.1-77.0). There were no significant differences in the proportions of those who planned to stay less than 5 years by income, but those who had lower acculturation and lower English proficiency planned to stay less than five years in significantly higher

proportions (21.22 and 18.39%, respectively) when compared with those with higher acculturation and higher English proficiency (1.6 and 3.0%, respectively). Most immigrants would like to stay in the U.S., but they had ambivalent feelings about this decision. One of the primary reasons to stay was economic. One of the most often cited reasons to go back was the need to educate children in their culture and values. Some Hispanics disliked the tendency of fellow Hispanics to criticize the U.S. and felt we should be grateful to be able to live in this country. They felt we should not complain about it.

Many Latinos in SWPA, especially those who felt that the U.S. is their permanent residence hope for a cohesive community. Usually, this was expressed in talk about what the ideal community would be, as opposed as what it is now. Some people believe it is time for the Latino community of this area to have a meeting place to call their own. Other people express the need to be *unidos* (united) or to have only ONE organization of Latinos, so that we are not divided. Frequently, people would like to see their children and younger family members involved in the community, so that they might see more “*gente como ellos*” (people like them). Some frequently referred to America as the “*Patria Grande*” (the big homeland). In those cases, they were talking about the concept of “*América*” that is common to all Latin America: The America that is one continent from Alaska to Chile, with all its inhabitants being “*americanos*”. Many of the same people identify themselves using pan-ethnic terms, such as “Latino” or “Hispanic”. They tend to be more concerned about how *our community* fares in SWPA. However, the sense of being permanently in the U.S. is not constant, and many have mixed feelings.

### ***Q. Solidarity and identification***

One way to assess the extent to which SWPA Latinos constitute a cohesive community is to look at community activities that could be seen as expressing solidarity. During the course of this study, I saw many, many examples of individual solidarity. Some individuals assisted newcomers of low income, either on their own or because they were contacted by agencies. One occasion, a provider told me that a 911 operator gave her name to a woman

who called the emergency system. She was able to help the woman in an informal way. In recent years the SWPA Latino community has organized itself for humanitarian causes. Individuals and organizations have worked hard to organize parties and concerts to raise funds to help the victims of natural disasters in Colombia, Venezuela, Peru, Nicaragua and Honduras. Another example of a humanitarian activity is LACU's organization of a Spanish-language orientation session to assist new university students. Both of these examples, although very different from each other, show solidarity between Latinos in the U.S. and people from the countries of origin.

What about those who were here and were having a hard time? Why was there no organized solidarity to benefit them? Were there any opportunities to show solidarity with them? In two separate occasions, during the participant observation period, relatives of three Mexican young men, who had died here, needed to send the bodies back to Mexico. They would not accept cremation, even though the priest said it was acceptable, because "*es sangre mexicana*" ("it is Mexican blood"). They collected money at church and from individuals. However, there was no organized community effort to help them. Some Latinos even contested the veracity of the request, thinking it might have been a scam (It turned out it was not, as I was able to confirm, with other sources in both cases.)

To qualify as activities that show solidarity and demonstrate community building, they have to be organized. There are no organized activities to help newcomers with lower (or no) English proficiency and without resources to settle here. Some view "social" concerns as a dangerous sign of leftist tendencies. For many, solidarity is good when it applies to helping people in Latin America, but not necessarily to helping Latinos in the U.S. A few long-time community members seemed to be unaware that there were low income Latinos arriving to the area. Others acknowledged their presence but did not consider them to be part of "the community." They defined them as "other" people. "Other" people were sometimes feared because they might be dangerous and criminals. Again we see that stereotypes also exist within the Latino community.

Zsembik and Beeghley (1996) define ethnic solidarity as the “commitment to collective action on behalf of the ethnic group” (p. 51) It is “most apparent when the ethnic group promotes or protects economic and political interests, actions that originate at the local level and sometimes coalesce into national mobilization and political empowerment” (p. 52). They say that its determinants are ethnic ties, ethnic identity, economic resources and class identity. The middle class is less likely to develop class identity. Its members have more economic resources and therefore, less need. That explains, in part, why our community, traditionally mostly middle class, has failed to produce a sense of ethnic solidarity.

According to Zsembik and Beeghley, the existence of ethnic solidarity promotes social and economic mobility of group members, as well as their political and economic integration into U.S. society. Ethnic solidarity means, for example, that supporting Latino businesses, supporting bilingual education and pressuring employers to hire more Latinos are regarded as “good things to do.” However, these are not the only possible ways to show solidarity. Zsembik and Beeghley argue that among middle class people, solidarity could also be shown as using positional power. For example, professionals could write letters, give speeches, and use professional networks to advocate for the benefit of the ethnic group. Most SWPA Latino professionals, especially health professionals, were not yet using the opportunities at hand to lobby for the needs of less favored Latinos in the area.

### ***R. Socioeconomic status and the definition of a group***

The way the “Latino community” is defined varies, from the very broad (all Latinos) to the very narrow. Some believe that now the Latino community in SWPA is too heterogeneous, making it difficult to find common interests. They tend to identify with a narrower group, divided by socioeconomic status. This kind of division happened among the poorer segments of the population, but it was more common among those who had more years of formal education. This might stem in part from the need to assert one's social status, as explained before. Additionally, some people expressed pride in being part of an exceptional

Latino community, one comprised mostly of professionals and students. They felt the status of the whole group would decrease as it became more heterogeneous. For example, one man felt that gone were the days when all Latinos used to get together once a week at a table of a local restaurant. Even at that time, some twenty years ago, there were more Latinos here than those who could sit at one single table; his perspective included only some of the upper class males in Pittsburgh as “all Latinos.” Another example of class tensions and divisions were apparent in comments elicited by a three-page article about local Latinos that appeared in the *Pittsburgh Post-Gazette* on Sunday, October 3, 1999 (Nelson-Jones, 1999). The article portrays Latinos as a complex and diverse group. The author interviewed people from all walks of life, including several professionals and businesspersons. However, some thought the article was demeaning. They thought it should not have shown the problems of the poorest segments of the population or that it should have avoided mentioning that some Latinos might have an uncertain immigration status. The article, in their view, damaged the image of the Latino community here. Another problem people have with the diversification of the Latino group in SWPA is that it might bring crime to the area. These fears were reinforced last year, when a Mexican man shot death two other Mexicans in Pittsburgh.

Immigration is a sensitive issue that is not unrelated to class. It is likely that the majority, but not all, of those with an uncertain immigration status are people of lower income and few years of formal schooling. Many informants mentioned the issue only indirectly, if at all. During the initial contacts with community members, I was advised repeatedly to be careful, because people tended to be afraid of interviewers, ever since an article about “illegal immigrants” appeared in the *Pittsburgh Post-Gazette* on Sunday, December 10, 1995 (Thomas, 1995). Although the article protected names, the way it described the workplaces of “illegal immigrants,” according to many, made it easier for the INS to find them. Interestingly, many of the individuals who warned me about the article had never read it.

### ***S. Country of origin and other conflicts***

There are several personal conflicts among members of the Latino population, as can be expected among members of any group. Some stem from gossip. Some are based upon competition in the market. Others are based upon competition between two people seeking prestige in the same way. There are some differences based on national origin. For example, some South Americans said they did not want to be associated with Caribbeans, citing their loudness and music as problematic. Also, some Caribbeans did not like to be associated with people from the Andes, believing them to be too quiet and introverted. It is impossible to know how many people feel this way, but only a few expressed those feelings during conversations. At the national level, frictions have been described. According to Gonzalez (2000), in the East, Puerto Ricans and Dominicans have run into problems as they perceived themselves to be fighting for the same jobs; the same type of friction has been described between Mexicans and Puerto Ricans. Gonzalez believes that the arrival of more Central and South Americans has diversified the environment and somehow eased the friction.

### ***T. Is this a cohesive community?***

The answer to this question depends on how we define “community.” In the past, communities were thought to be geographically delimited. Now, more and more people are referring to communities as groups of people that are connected for reasons other than physical space or neighborhood. Israel et al (1998, cited by Annual Review of Public Health, 1998), believe that communities are socially constructed units of identity, created and recreated through social interactions. They say a community is characterized by a sense of identification and emotional connection to other members, common symbol systems, shared values and norms, common interests, and commitment to meeting shared needs. This is the case of Puerto Ricans and Latinos on the West Coast (Keefe 1980, Silvestrini 1997). Today, communities are less well defined than before.

People can enter and leave a group more easily as cultural norms are “hybrid and creolized” (Bibeau, 1997). Bibeau adds,

“Individuals and societies seem to have entered a permanent transitional state, with fuzzy boundaries that make human groups and individuals fragile as new possibilities emerge, and with worldviews that have multiple referents that make individual behavior less self-reproducing and less predictable....”  
(p. 249)

There is no geographically defined Latino community in SWPA, no place we could call *barrio*. However, if we think of community not only as people sharing a physical space, but also as those who share a cultural space, cultural characteristics, or are interrelated, the picture could change. Other “indicators” to find out whether this is a cohesive community are large numbers, homogeneity of the population, shared values, beliefs and practices, ethnic identification, degree of organization, ethnic solidarity, and the existence of “sacred places.”

The three written accounts on Latinos in SWPA each address the issue of community to some extent. Holly (1997) talked to Latino health professionals and a few other Latinos to prepare a short paper arguing for the need of translators in mental health services. She says that it is difficult to organize the community in SWPA due to economic and territorial problems in the countries of origin. I found no evidence of this. On the contrary, people from countries that had border disputes seemed to get along better here than in Latin America. Perhaps here they learned more about the ones they formerly saw as “others” and re-defined them as part of “us”, or perhaps they saw border conflicts as something that did not affect them directly. Additionally, economic hardship and tragedy seemed to bring about solidarity, rather than conflict. In a class paper about the Latino community in the area, Wilson (1998) said that there is no Latino community in the area, rather the population exists in pockets, separated by class differences. Wilson’s paper is limited by the number of people she contacted and studied. For example, it gives the impression that most Latinos in the area are from Venezuela and Peru. Perhaps due to that limitation she failed to notice the communities that existed in those population

pockets and the networks that connected many of those pockets to one another. Of course, there are isolated people, and I could not find everybody for this research, either. Patrick (1973) interviewed an unknown number of Hispanics in Pittsburgh to find out the extent to which a community existed. His indicators were geographical location, existence of organizations of Hispanics, desire to have a community, and degree to which Hispanics helped one another in an organized manner. At that time, people were even more scattered than today, they were largely unaware of the number of Hispanics in Pittsburgh, and solidarity was virtually non-existent.

Factors that promote acculturation are small population size, high level of education, urbanization and mobility (Saunders, 1954). A small group “dilutes” into the mainstream. This is easier in a city, and happened earlier this century in SWPA. Currently, in SWPA, the conditions are changing, and the population is growing and communicating better. Furthermore, the importance of high level of education in promoting acculturation is decreasing, as the revival of all things ethnic, not just Latino, pervades the middle class.

Hispanics who came to SWPA from different countries and are of different socioeconomic strata share similar values regarding family and education. People are connected by the same national origin, religious affiliation, mutual affinity, or other reasons. Often, people of different socioeconomic backgrounds celebrate the same traditions. There is a degree of shared values, beliefs and practices. There are several groups that communicate with each other. They participate in ethnic networks, although they might be limited in scope and have a certain feeling of ethnic identification. There might be incipient “sacred places,” such as the Catholic mass, the CLAS festival, and perhaps an Oakland restaurant. Organizations are loose and limited; ethnic solidarity is more private than organized. There are groups that do not communicate much with others and it is quite likely that there are others more isolated groups. I was not able to identify any, perhaps due to that very isolation. There might be isolated individuals, living everyday within the Anglo community, and not relating much with other Latinos. Class, politics and nationality issues separate individuals. The greatest source of division appears to be social class. The interests of the more educated groups, remain, in large

part, “cultural issues,” although there is a tendency to consider other issues to be important, too. Comparing the community that Patrick described in 1973 to the community revealed in the course of my study, there has been some development towards a more connected group, partly due to the creation of several more Latino organizations, but there is still no grassroots engine for its formation. Latinos in SWPA do not constitute a cohesive community; rather they form a set of small, overlapping communities.

### ***U. Summary***

Latinos in SWPA are a varied group with an overrepresentation of South Americans, relative to other areas in the U.S. The paths of migration have been similar to the paths of migration of Latinos elsewhere in the U.S. However, blue-collar workers, typically comprised largely of Mexicans, Central Americans and Caribbeans, failed to come to SWPA due to the economic decline of industry in the 1970s and 1980s.

Latinos in SWPA hold diverse jobs, ranging from professional positions to service jobs. Although a few had high incomes, income was generally low relative to years of schooling. This happened because of language barriers, as well as immigration and degree certification issues. Given that income was generally not very different among socioeconomic subgroups, people with more years of formal schooling felt the need to make their educational achievements known, as a way to differentiate themselves from those with fewer years of schooling.

Latinos share a concept of family as an extended network that is important in every aspect of a person’s life. Most Latinos share interest in cultural values and traditions, such as food, dance and music. They are preoccupied with passing that interest to their children. Latinos might belong to several religious groups, and those groups serve also as points of contact for building social networks. Even though Latinos have increased in numbers, there are still few organizations. The organizations that exist are mainly concerned with cultural issues.

The question of whether or not this is a cohesive community is considered from the perspective that communities are not necessarily geographically delimited. Rather, they are social constructions, imagined communities, based upon similar values, cultural norms and symbols. The factors uniting Latinos are traditions, language, ethnic networks and a limited sense of group identification. There are a few places that can be called “sacred places,” and there is hope for a more cohesive group among many in this population. The factors that united Latinos stem mostly from the need to belong to a group and to reproduce certain characteristics of life, such as family networks. However, there are still relatively few Latinos in the area that need to unite due to pressing material needs. Being middle class, many have not needed to defend their rights in U.S. society, or have not realized the need. Therefore, attachment to the ethnic group is not strong. Discrimination plays a small role in community formation, even when many members of the group experience it to some extent. Geographical separation, small numbers, and lack of class identification or concern are obstacles for the development of a cohesive community. However, the greatest obstacle is conflict along socioeconomic lines. This conflict is especially evident in situations of change or crisis, such as the impending relocation of the weekly Spanish-language Catholic mass, or the death of Mexican men. In summary, we can say that Latinos in SWPA do not constitute a cohesive community, but rather a set of small overlapping communities connected to each other by ethnic networks, and many isolated small groups.

## **V. Health and health beliefs**

### ***A. Introduction***

Health status and health beliefs are known to affect health care needs and health care seeking behaviors. In this chapter, I will present data on health status of Latinos in southwestern Pennsylvania (SWPA), as perceived by themselves. Data on health beliefs and attitudes were not the main focus of this study. However, some characteristics of health beliefs and attitudes were captured by the qualitative data, and they are discussed. They relate to a holistic view of health, pluralism in health beliefs, and fatalism.

### ***B. Perception of health status***

#### 1. General health

In general, Latinos in SWPA perceive themselves as being healthy, although some report chronic conditions. As shown in table 25, in this research, the weighted proportion of people that reported their health status as fair or poor was 17.7%, similar to national data of 15.3% presented by Hajat et al (2000). Andersen (1995) and Hajat et al (2000) found that perceived health status is related to education, country of origin and sex. In SWPA, the proportions of people with lower income, acculturation, and English proficiency that reported fair or poor health was larger than those with higher income, acculturation and English proficiency. However, the confidence intervals of the weighted estimates for SWPA showed no statistically significant difference in perceived health status by income, acculturation of English proficiency. Females and males reported being in fair or poor health in similar proportions.

The SF12 scale provides measures of physical and mental health status. In general, 39.6% of Latinos in SWPA considered they had a physical health status below the median for the U.S. population.

Nationally, Latinos experience relatively good health status as a group, given their low average socioeconomic conditions. Some differences in health status might exist due to income, language and acculturation in SWPA that the data could not show because the confidence intervals were wide, reflecting a small sample.

**Table 25**

**Latinos in southwestern Pennsylvania who self reported their health status as “Poor” or “Fair” by income, acculturation and English proficiency. Weighted estimates and confidence intervals**

|  | Percentage<br>(95% Confidence interval) |
|--|---|
| All Latinos                                  | 17.7 (9.8 – 25.6)                       |
| Latino men                                   | 20.9 (10.3 – 31.5)                      |
| Latina women                                 | 15.3 (4.5 – 26.0)                       |
| Latinos with lower income (<\$20,000/year)   | 30.0 (10.1 – 43.9)                      |
| Latinos with higher income (>=\$20,000/year) | 8.7 (2.3 – 15.0)                        |
| Latinos with lower acculturation             | 26.4 (16.6 – 36.3)                      |
| Latinos with higher acculturation            | 8.1 (0.0 – 17.9)                        |
| Latinos with lower English proficiency       | 21.5 (9.4 – 33.6)                       |
| Latinos with higher English proficiency      | 12.5 (1.4 – 23.6)                       |

Weights for probability of selection, non-response, and post-stratification were applied.

**Table 26**

**Latinos in southwestern Pennsylvania who had physical health status below the U.S. median in the SF-12 Scale, by income, acculturation and English proficiency**  
**Weighted estimates and confidence intervals**

---

|  | Percentage                |
|--|---------------------------|
|  | (95% Confidence interval) |
| All Latinos                                  | 39.6 (27.5 – 51.8)        |
| Latinos with lower income (<\$20,000/year)   | 39.4 (17.5 – 61.2)        |
| Latinos with higher income (>=\$20,000/year) | 39.9 (29.5 – 50.4)        |
| Latinos with lower acculturation             | 50.4 (39.9 – 60.9)        |
| Latinos with higher acculturation            | 27.8 (9.9 – 45.6)         |
| Latinos with lower English proficiency       | 33.9 (17.5 – 50.3)        |
| Latinos with higher English proficiency      | 47.7 (34.4 – 60.9)        |

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Weights for probability of selection, non-response, and post-stratification were applied.

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## 2. Mental health

Forty-one percent of Latinos in SWPA reported mental health status below the median for the U.S. There were no significant differences for these measures by sex, income, English proficiency or acculturation.

**Table 27**

**Latinos in southwestern Pennsylvania who had mental health status below the U.S. median in the SF-12 Scale, by income, acculturation and English proficiency. Weighted estimates and confidence intervals**

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|  | Percentage<br>(95% Confidence interval) |               |
|--|---|---------------|
| All Latinos                                  | 40.6                                    | (28.3 – 52.8) |
| Latinos with lower income (<\$20,000/year)   | 44.1                                    | (20.1 – 68.0) |
| Latinos with higher income (>=\$20,000/year) | 37.1                                    | (27.3 – 47.0) |
| Latinos with lower acculturation             | 47.0                                    | (36.4 – 57.6) |
| Latinos with higher acculturation            | 33.4                                    | (13.3 – 53.6) |
| Latinos with lower English proficiency       | 36.5                                    | (19.1 – 53.9) |
| Latinos with higher English proficiency      | 46.2                                    | (33.0 – 59.4) |

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Weights for probability of selection, non-response, and post-stratification were applied.

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Some interviewees were concerned because they felt there was too little about mental health and social problems in the interview and they wanted those concerns to be captured by the research. Many Latinos voiced feelings of isolation. Such feelings tended to be more frequently expressed by people who had been here a short time and had not yet had the opportunity to find other Latinos. However, some still felt isolated after a long time. Some had tried to fit into U.S. society and failed. Now they were trying to find others “like them.” For immigrants, one of the reasons of feeling isolated was the absence of the family, especially the extended family. Another reason was the realization that their culture did not match U.S. culture. Ways to do everyday things and interpret

reality were different. Both reasons are likely to change over time, as the immigrant becomes used to U.S. culture, establishes more connections, brings his/her family to the U.S., and builds a network of fictive kin. Many actively sought fictive kin relationships by attending events, church services, or local organizations. Others had a more difficult time finding connections. They were bored and felt powerless. Isolation was particularly problematic for homemakers who do not speak English, when they are relatively disconnected from the other Latinos in SWPA. Several of them expressed their concerns to me, and some became emotional during the conversation.

Some Hispanics who work outside the home, found being at work and working long hours to be a temporal “solution” to their problem, as being busy did not allow them to worry and feel nostalgic all the time. Working long hours has some drawbacks, including that it might perpetuate feelings of isolation, as it does not allow people time to socialize. Such is the case of Alejo, who works as kitchen help in Allegheny County. He came here because of competitive wages and because his brother was also in town. However, they work at different places and live one hour apart, by bus. Since they each work more than 10 hours a day, including weekends, they could see each other only when both of them happened to have the same day free. Also, Alejo lived with five other immigrants like him, but they had little time to talk. They usually slept at night. Alejo liked working long hours, because in that way he did not think of his family back in his country and how much he missed them. Talking about this was difficult for him, but he thought he was lucky, because he could leave once a year for a month or two and visit his mother. Then, he could come back and still find a job here.

Rogler (1983) points out that immigration can affect mental health because a new sociocultural system creates new forms of stress. It disrupts the family cycle and the family structure, it prompts responses such as acculturation, and it forces immigrants to face external barriers, such as discrimination and a different language. Pérez-Montijo (1996) talks about a “relocation stress syndrome,” that surfaces when individuals are dislocated from their environment and feel powerless dealing with an impersonal system. Here in SWPA, those who had fewer economic resources to confront the new

challenges were more prone to suffer mental health problems. However, responses also varied by country of origin, sex and other characteristics. Whatever the case, newcomers need to find a community, to become involved in it, and to feel connected. Developing a sense of belonging and feelings of material and emotional support can be more difficult due to the lack of a cohesive community. Resources within the Latino group are more scarce and also more difficult to find.

### 3. Domestic abuse

Another health problem I heard about often was domestic abuse. It was mentioned quite a few times, by victims themselves, by their neighbors, or by people who had the opportunity to assist them. I heard reports about abuse of at least six different women from four different countries. They were subject to physical, sexual, verbal, and psychological abuse. Some victims were married to abusive Latino men, but most accounts were of women married to abusive Anglo men. It was not clear whether they were just more prone to speak out than the ones married to Latino men, or whether this latter group were really more frequently abused. Giachello (1996 b) says that Latinas in the U.S. are often victims of domestic abuse, but I could not find any statistics regarding this issue.

Some Latina women in SWPA came to the U.S. after marrying a U.S. citizen and found themselves in a strange land with different customs. Often, they had low (or no) English proficiency and did not drive a car. After the abuse started, it was difficult for the women to leave. Their husbands controlled the household economy and were gatekeepers to relationships with people outside the home. They threatened to stop their wives' immigration paperwork if they told anybody of the abuse or left the house. In one case, a man did not allow his wife to talk to any other people, to learn English, to drive or to work. He wanted her to stay at home and have many children. Most importantly, several abusive men told their wives that their children were U.S. citizens, and that, under U.S. law, the husband had custody. The mother might leave, but the children had to stay. According to several providers and to people who have assisted these women on some occasions, the abusive men married Latinas expecting that

they would embody the stereotype of the devoted wife at home all day and compliant to all her husband's wishes. When the women did not fulfill these expectations, the men felt frustrated and abuse started.

### **C. Health beliefs**

#### 1. Holistic view of health

Latinos are said to have a holistic concept of health, involving all aspects of one's life, not only the body. Schensul and Schensul (1982) say that for Latinos there is no distinction between physiological and physical problems. Rivera-Tovar (2000) says that body and mind are "obviously" inseparable to any Latino, but that is not the case for the U.S. health system. According to Bassford (1995) and St. Germain and Longman (1993), the Spanish word *enfermedad* encompasses both concepts of "disease" and "illness." In English, St. Germain and Longman say, "disease" refers to the bodily events and processes, and "illness" to the sociocultural constructs and behavioral responses to disease. St. Germain and Longman (1993) explain that *enfermedad* includes the spiritual, moral, somatic, physiological, psychological, metaphysical, and social aspects of a disruption in health status. According to Giachello (1996 b), being healthy means that the person behaves in accordance with God, his or her conscience and the norms of the group. This might be the reason why several folk diseases, like *nervios* (Fabrega, 1990; Low, 1994) and *calor* (Jenkins & Valiente, 1994) are precipitated or worsened by family tensions and social stressors. Although not somatic in origin, they manifest as somatic changes. The existence and acceptance of these syndromes points out a more holistic view of health.

From the data of this research, little can be concluded regarding this topic; health beliefs were not the study's focus. However, some details about health beliefs appeared casually in conversations with Latinos in SWPA. For example, people at almost every social gathering recommended to those who were leaving that they be careful with the cold, which could affect your health. It was common to hear talk about the harm that the cold air could do or about the harm brought by exposure to heat and cold in succession. When asked

about it, some cited their grandmothers and other family women as a reference for their knowledge in this area. I found these humoral concepts, as well as some humoral-based treatments, among people of all social classes, at all levels of education and from several different countries of origin. For example, Régulo, a doctoral candidate, inquired about a wrist brace I had on my right hand. When I replied that I had carpal tunnel syndrome caused by typing, he smiled and said that he knew that typing was not the cause. He was sure, he said, that I had made the same mistake so many women make: to iron clothes and then to wash dishes in cold water. It was no surprise to him that I felt pain in my arm. On another occasion, Gerardo, a researcher and professor in one of the health sciences at a local university, commented on taking care to avoid the cold air. I asked how he knew that the cold air was a cause of disease. From his mother and grandmother, of course, he answered. He was alarmed and intrigued at my apparent lack of knowledge on something so important that he considered very basic knowledge. However, he never mentioned anything about research that supported his beliefs.

Foster explains that humoral medicine is a holistic theory of health maintaining that disease is an imbalance caused by an excess or defect of one of four humors: hot, cold, wet, and dry. Treatment consists in alleviating the imbalance by restoring the proper amount of each humor (Foster, 1995; Ruiz, 1985). Being careful with the cold air would be a primary prevention measure. According to Foster (1995), the humoral medical theory was originally Greek and arrived to Spain in the eight century with the Arabs. At that time, this was the most advanced theory of medicine and the Spanish elite, especially the clergy, brought it to America. These beliefs never made a great impact among the Spanish populace and were eventually replaced by other theories of disease. In America, the situation was different. Priests ran missions, taught the native population, treated illnesses, and also administered the first hospitals. Additionally, countries such as Mexico, Peru and Chile kept the humoral theory-based writings from Avicenna as textbooks in their schools of medicine until well into the nineteenth century. Perhaps this is why these beliefs, including the same names to designate diseases and treatments, have been found in many countries, including Brazil, Colombia, Haiti, Mexico, Peru,

Puerto Rico, and even the Philippines. Foster says that in the United States, traces of these beliefs can be found, but only as an explanation of disease; the rest of the theory has been lost.

Foster maintains that humoral beliefs are pervasive among all social classes, as found, with very limited numbers, in the SWPA sample. This might be just another way in which Latinos are culturally similar, but it is a similitude that often goes unnoticed, due to the “obviousness” of these beliefs to most Hispanics. Also, Reichman (1997) found that it is not necessarily true that less acculturated Latinos cling to more “traditional” ideas of illness and medicine, and it is not true that language ability is a good predictor of what health beliefs a person may hold. Some English-speaking Latinos may believe in *curanderos* (medicine men) or witchcraft. Some Spanish-speaking ones may not. This contrasts with some, such as Haffner (1992), who maintain that highly educated and affluent Latinos have attitudes and beliefs about health and health care reasonably comparable to those of similarly educated and wealthy individuals from the United States. Haffner presents no data, and her claims may be more grounded in class-based stereotypes than real facts.

## 2. Pluralism

For the most part, Latinos in SWPA adhere to the biomedical model of health and disease, but many hold pluralistic beliefs about health, illness and treatments, and see no contradiction between them. Most people trust their doctors. However, a few distrusted allopathic western medicine in general, which they referred to as “commercial medicine.” Some disliked using antibiotics, feeling the drugs would damage the immune system; one person said that the continuous use of antibiotics heightened resistance of the body to antibiotics. One woman did not like to take medicines because they would hurt her stomach, yet she took several different herbal preparations each day “to stay healthy.” Some of the herbal preparations were made from herbs she dug in her yard, some were commercially available.

Only seven interviewees admitted having used a *curandero* in the past year. During participant observation, a few more Latinos commented about their use of *curanderos* or herbs. Most people who used herbal medicine,

*curanderos* or *hueseros* (folk bone healers), also used chiropractors to “fix energy blocks,” or regular MDs for other diseases. Some followed the recommendations of a *curandero*, and some have learned what to use for each illness from their mothers and grandmothers. However, only one woman among those I spoke with explained in detail how to diagnose and treat diseases based on herbal knowledge. She described the preparation of herbal medicines in great detail, for at least four distinct diseases. Other people used herbal medicine, but did not know how to diagnose many diseases or what the treatment might be. They resorted to asking a *curandero* or an *herbolario* (herbal doctor, a person who is knowledgeable about herb remedies, or even a person who sells herbs). Currently, there is no *curandero* in the SWPA area. However, one interviewee said there had been a Mexican *curandero* in the area relatively recently, but he had left a few months ago. Some revealed that they got herbs from a *curandero* when they traveled back to their countries of origin. Others got them from *curanderos* when they traveled to Florida, New York or California. Some combined the use of Latin American traditional medicine with other cures originally from Africa or Asia. These could be found in local stores in SWPA or obtained from friends from those continents. This kind of behavior was found among both, people with few and those with many years of formal schooling, as well as among people and from countries as different as Argentina, Colombia and Mexico. Alicia, a woman in her thirties with a Master's degree, was trying to find somebody who could cure her nephew of *susto*, a folk illness. It did not matter to her that the nephew's mother was a doctor. Most, if not all, people mentioned in this paragraph also used western medicine. Doctors were generally well respected and their services highly valued.

Several people adamantly said that they had never used *curanderos*. Some found the question, a standard part of the survey, to be insulting. They felt it was a suggestion that they were ignorant or simple people. One person responded in a loud voice, “*No, no, no, pero está loca, discúlpeme Ud., pero cómo se le ocurre? [pausa] No tengo, nunca he tenido confianza en esa gente, mi salud yo la respeto mucho!*” (“No, no, no, are you crazy? How can this occur to you? [pause] I don't trust, I have never trusted those people, I respect my health very much!”) Some did not want to use *curanderos* any more, due to a negative

experience. Teófilo had used the services of a *curandero* in the past for a liver problem. After getting coffee enemas and some herbs, he felt a little bit better. However, as months passed, his condition worsened, and Teófilo ultimately needed a liver transplant. He and his family declared they would never again consult with a *curandero*. Sara said she did not like folk medicine, because it was evil. Her grandmother had applied a massage or “*sobado*” to a baby in the family, long ago, worsening the baby’s condition. Interestingly, Sara doesn’t believe folk medicine is ineffective. Instead, she believes folk cures have power; but that it is negative power.

Ruiz (1985) maintains that Latinos in the U.S. commonly believe in *curanderos*. Giachello (1996 b) says that Latinos seek professional care only when *curanderos* are not available. However, she also says that some people may use *curanderos* because of a past negative experience with the western health system, especially problems related to doctor-patient relationship. Freidenberg et al (1993) maintains that the infrequent use of *curanderos* in some areas stems more from their lack of availability than lack of credibility. This might be the case in SWPA, but more data would be needed to confirm it.

A few people, mostly middle class, preferred “natural” medicine, also called “alternative medicine” to western allopathic medicine. They were careful to point out that they did not use any *curanderos*, only natural cures, as used in the Far East. Miles (1998) found that in poor urban Ecuador quite often people use “natural” medicine, as packaged for international markets. She argues that they do so to validate their beliefs as rural origin urban dwellers, but at the same time, to feel modern and sophisticated. Latinos in SWPA might be trying to do the opposite: to differentiate themselves both from “ignorant” people who use witchcraft for their healing and from those who adhere blindly to the biomedical model, ignoring a holistic interpretation of health. In this way, they try to establish themselves as modern, sophisticated users of the trendy “natural” medicine, packaged in clean containers.

Most health-related beliefs and practices of Latinos in SWPA are of the natural sort. That is, it was germs, the “cold,” herbs, massages, prescriptions, and other natural stimuli that could cause a condition, cure or better it. Very few people believe in magical or supernatural causes or cures, such as

witchcraft or the punishment of God. Although these causes are often described in the literature (Ruiz, 1995; Ruiz, 1985; St. Germain & Longman, 1993) and in popular media (Kilborn, 1999), I found few Latinos that used both spiritual healers and MDs. Nobody told me they or someone they knew suffered from witchcraft. This might be because this belief was not considered to be as important, because I did not really look for it, or because it was a sensitive issue that was not easily elicited in the context of participant observation and informal conversations.

The pluralism found in SWPA was not surprising. It is commonly found among Latin Americans and among Latinos in the U.S. Freidenberg et al (1993) found that in East Harlem, NY, elderly residents hold pluralistic views about health and illness and that although they use biomedical providers, many also use popular and folk medicines. Pérez-Montijo et al (1996) found that Puerto Ricans in Hartford, believe that doctors are the best source of care, but also that *curanderos* are effective. Saint-Germain and Longman (1993) reported similar findings about Hispanics mainly of Mexican origin in Tucson, AZ. Browner (1998) points out that different rationales inform folk and biomedical practices. Lay people tend to assimilate parts of the biomedical model and adapt it to their own uses. The result might be a practice that is neither ancient nor modern. For example, the administering of lay injections is widespread both in the Third World and among Latinos in the U.S. (Marin, 1989; McVea, 1997). McVea found that Mexican migrant workers in the U.S. regard injections as having properties other than the ones biomedicine accepts. They believe the injected substance has somehow different (better, stronger) curative qualities than the same substance administered in some other way. This is a reinterpretation of biomedical practices in light of some other existing illness paradigm.

When a group of people achieves a specific level of agreement on the elements within a cultural domain, they are said to have agreed on a cultural model (Chavez et al, 1995). Biomedical providers often perceive elements of these models as “misconceptions.” An ethnographic study of poor women and breast cancer belief models found that Salvadoran and Mexican women share a cultural model regarding cancer. Interestingly, *Chicanas* had a different model,

one that had some elements of the model of Latin American women and some from the model of Anglo women, all integrated into a coherent view of breast cancer causes (Chavez et al, 1995). According to Moreno et al (1997), populations that are in a process of acculturation tend to modify their old beliefs to new information received. However, this might not entail changing from one end of the spectrum to the other, but combining these beliefs. Chavez's research was done with poor women and we really do not know whether more affluent women share the same beliefs. Rogler (1983) focuses on acculturation and not SES as the basis of different beliefs. He says that belief in prayer as a healer and in mental illness as hereditary are correlated with being a Spanish speaker and first generation immigrant.

In SWPA, it appears that most Latino immigrants come to the U.S. already holding pluralistic views of health and illness. After all, most come from societies where the official system of medicine is biomedical. These societies are fairly well connected with U.S. culture, at least through mass media and trade. Browner (1998) says,

“Rather than drawing on a fixed or consistent set of principles, most lay understandings of and strategies for dealing with illness episodes are neither independent of culture nor determinate. Instead, they are shifting, emergent, and derived from the ongoing application of cultural and personal knowledge...[M]ultiple explanatory frameworks may coexist in many different types of settings...[R]easoning about health is not static, but instead continually incorporates new experiences and emergent information.” (p. 356)

### 3. Fatalism

The literature often reports that Latinos are fatalistic, have no sense of control over their lives, and fall into inaction because they leave everything to luck, fate, or the will of God (Goldsmith, 1993; Quesada, 1976; Ruiz, 1995; Saunders, 1954). Fate is inescapable, illness must be endured, and acceptance and resignation are the appropriate attitudes (Saunders, 1954; Brink, 1994). Often times in popular culture, faith is mentioned as a barrier to health care, (Kilborn, 1999) and sense of destiny has negative connotations (Ruiz, 1995). These beliefs are supposed to be lost with acculturation (Rogler, 1983). However, Oboler (1997) says that the image of the fatalistic Latino is part of a

stereotype maintained by popular media and academics. Indeed, often these assertions are made without any research base, and most of the time the writers present these attitudes from the point of view of the “norm” or “default” thinking, namely, U.S. people’s viewpoints. For example, Roll et al (1974) found that Mexican American university students were much more likely to have dreams about death than Anglos. They said that this could be part of a system of beliefs pervasive to any Hispanic country, since Hispanic people are more fatalistic. However, this interpretation does not consider the possibility that the Mexican Americans are more likely to see death as a part of life and Anglos are trying to deny death. From a Latino point of view, Anglos might be overly preoccupied with controlling their fate. As Browner (1998) explains when talking about decision-making studies, “our fascination with decision-making studies may be due to the peculiarly American preoccupation with the illusion that we control our destiny.”

Schur and Albers (1996) analyzed health belief data from the 1987 National Medical Expenditure Survey (NMES), and their findings were mixed. Both Spanish and English speaking Hispanics trusted the medical system. However, a significantly higher proportion of those who spoke Spanish only reported believing that luck played a big part in determining how soon they would recover from an illness, than other groups of Hispanics. A significantly smaller proportion of those who spoke Spanish only, relative to other groups, believed that if they were sick, it was their own behavior that determined how soon they would recover. However, a significantly smaller proportion of those who spoke Spanish only, relative to other groups, believed that they could overcome most illnesses without the help of a medically trained professional. Language ability made no difference in the proportion of those who thought home remedies were better than drugs prescribed by a doctor or that a doctor would never recommend surgery unless there was no other way to solve the problem. Schur and Albers also thought that the responses of Spanish-only-speaking Latinos reflected a weaker sense of control over their health, but they admit to not knowing whether this stems from feelings of powerlessness or a rational result of believing that health is largely beyond individual control.

There are some indications in the literature that fatalism is not as widespread as popularly believed. Nápoles Springer et al (1996) found that fatalism was not a determinant of seeking preventive care for Latinas. Saint-Germain and Longman (1993) found that women in Tucson, AZ, commonly believe that health and illness, specifically breast cancer, is related to fortune, punishment, luck and God's will. Resignation and acceptance of God's will, rather than anger, are the common responses to the possibility of cancer. However, a third of the women list specific actions they would take for their own good if faced with breast cancer. Additionally, resourcefulness is as typical a response as resignation. In some cases, the expectation of failure in the system may lead to the belief that nothing can be done. However, that expectation may be grounded in real experiences. Freidenberg and Hammer (1998) argue that perceived barriers of health care may lead elderly Latinos in East Harlem, NY, to resort to home remedies and prayer. Cross-sectional studies, especially quantitative ones, do not allow determination of whether fatalism is the cause of the problem or the problem is the cause of fatalism. Similarly, Friedl (1978) cites Franklin saying that coal miners are fatalistic due to the harsh conditions they endure, especially in coal mines. In other words, they do not have a short and bad life because they are fatalistic, but rather they develop fatalism because they have a short and bad life.

The questions that arose during this research were, Are Latinos fatalistic? Do they feel they have control over their lives or not? Do they try to find solutions to their problems, or do they wait to see what happens? Do they put themselves in the hands of God before or after they try to change their situation? According to the limited data gathered for this research, in many cases, people hoped God would protect them from disease. However, if they needed care, most people tried to get it. If they had no insurance, they might try to find care through a formal or an informal arrangement. Some could not get any care or had their problem only partially solved; these people might resort to home care only. Lack of information in a loosely knit population group made finding appropriate care more difficult. Only when there were no other options, did people I talked with comfort themselves by thinking that their problems were God's will. In that case, believing that they had no more control over what

happened was quite realistic. Accepting “destiny” and abandoning themselves to God’s will appeared to be a resource to cope with insurmountable problems rather than a sign of losing control. After all, a poor, uninsured worker with an unstable immigration status working 11 hours a day for a meager salary had not much real control over his or her life.

Other examples of action when facing a health problem were the women who suffered from abuse. In the cases I heard about, most of the women were not passive. Some women in abusive situations sought the help of Anglo and, if possible, Latino providers. For example, one woman managed to pay cash for a contraceptive injection so that her husband would not be aware of it, yet she could avoid conceiving a third child. Sometimes women experienced discrimination when they tried to find help, and their stories of abuse were ridiculed in court or by the police. Some even told of being threatened by policemen. Legal help was difficult to come by. Few lawyers would take up the case of an immigrant who spoke no English, had no money to pay them and had an immigration situation that was precarious. These women tried to find a way out of their situation and responded to it the best they could, even when it was really difficult. These women looked for help, but there might be others who did not that I could not contact. According to Chavira-Prado (1992) Mexican American women stay with abusive husbands not because they find the situation acceptable, but because they and their children cannot easily survive without a male partner.

The question remains, Was this belief in destiny or God’s will a coping mechanism after all other alternatives had been exhausted, or was it part of a belief system that precluded Latinos from action? This point is not clear and should be further investigated.

#### ***D. Summary***

Latinos in SWPA were generally healthy, and their physical and mental health status, as measured by standardized scales, was not significantly different from that of the U.S. population in general. Qualitative data suggest that there were some other health problems, relating to mental health issues,

such as social isolation and domestic abuse, but current data are scarce, and it is impossible to make any definitive statements.

From qualitative data, there were some indications that Latinos in SWPA have a holistic concept of health, one that includes both body and mind as one entity, as opposed to two separate entities. There are also indications that Latinos have pluralistic beliefs about health and health care. In general, they hold the biomedical system in high regard, but many also consider alternative explanations or cures derived from herbal medicine and humoral theories of health, to cite two examples. Most Latinos do not see any contradiction in these different beliefs, as has also been described in the literature.

Latinos are often portrayed as fatalistic. Although it was not the focus of this research, I found a few indications that this is not necessarily true. Latinos' acceptance of God's will seemed to be a coping mechanism, after all other options had been pursued. However, the question of locus of control, and whether Latinos are fatalistic or have a realistic understanding of their own limitations remains unanswered.

## **VI. Potential access to health care**

### ***A. Introduction***

Potential access to health refers to those dimensions that enable the individual to obtain care, such as having health insurance and a regular source of care. In this section, survey results for these two indicators are analyzed. Health insurance is by far the most widely used measure of access to care. Additionally, I will explore how financial and cultural factors affect access to health care, based on results of the survey and participant observation. Specifically, I will explore the effects of socioeconomic conditions, information level, language and country of origin.

### ***B. Measures of potential access to health care***

#### 1. Health insurance

The weighted proportion of uninsured Latinos in southwestern Pennsylvania (SWPA) was 38.1% (95% confidence interval 21.7-54.5). This is similar to the proportion of uninsured Latinos at the national level reported during the last decade, which ranged from 33.5 to 39%. It also corresponds with data obtained from different national level surveys, such as the Current Population Survey, the National Medical Expenditure Survey, and the National Health Interview Survey (See Table 28). That the proportion of uninsured Latinos in SWPA is similar to the proportion of uninsured Latinos nationwide defies expectations. First, the Latino population of SWPA is supposed to be mostly middle class. Second, the proportion of uninsured Latinos is reportedly smaller in the Eastern United States than in other areas of the country

(Burciaga Valdez et al, 1993). Third, it is assumed that the bias of the sampling frame favored higher socioeconomic status groups.

**Table 28**

**Weighted percentage of uninsured Latinos in southwestern Pennsylvania, compared to results of national surveys**

|   | Percentage |
|---|------------|
| Latinos in southwestern Pennsylvania 1998-1999 <sup>a</sup> | 38.1       |
| Latinos in the United States CPS 1998 <sup>b</sup>          | 37.0       |
| Latinos in the United States MEPS 1996 <sup>c</sup>         | 33.5       |
| Latinos in the United States NHIS 1994-1995 <sup>d</sup>    | 34.5       |
| Latinos in the United States CPS 1990 <sup>e</sup>          | 39.0       |
| Latinos in the United States NMES 1987 <sup>f</sup>         | 35.0       |
| Latinos in the United States CPS 1980 <sup>e</sup>          | 25.7       |

<sup>a</sup> Data were weighted for probability of selection, non-response, and post-stratification.

<sup>b</sup> Brown et al 2000, includes people <65 years of age.

<sup>c</sup> Kass et al 1999, includes people of all ages.

<sup>d</sup> HRSA 1999, includes people between ages 18 and 65.

<sup>e</sup> Burciaga-Valdez et al, 1993, includes people <65 years of age.

<sup>f</sup> Schur and Albers 1996, includes people >=18 years of age.

As expected, study results show the percentage of uninsured Hispanics to be significantly larger among those with annual family income under \$20,000 than among those with higher income (Table 29). However, there is no significant difference by acculturation level or English proficiency. Logistic regression showed that, after controlling for region of birth, education, and acculturation, people who have annual family incomes equal or greater than \$20,000 are approximately seven times as likely to be insured as those with lower incomes (See Table 30). Acculturation, however, did not prove to be a significant determinant of insurance status in multivariate logistic regression. Additionally, those who had at least some college education were seven times as likely to be insured as those who had fewer years of formal education, independently of the effect of income. Region of birth significantly affected

insurance status, but the odds ratio was not different from zero. Other variables were not significant determinants of insurance status.

**Table 29**

**Weighted percentage of uninsured Latinos in southwestern Pennsylvania by income, English proficiency and acculturation. Weighted estimates and confidence intervals**

|  | Percentage | 95% Confidence interval |
|--|------------|-------------------------|
| All  | 38.1       | 21.7 – 54.5             |
| Latinos with annual family income <\$20,000  | 64.4       | 44.2 – 84.6             |
| Latinos with annual family income >=\$20,000 | 12.2       | 4.0 – 20.3              |
| Latinos with lower English proficiency       | 50.9       | 29.0 – 72.8             |
| Latinos with high English proficiency        | 20.2       | 7.9 – 32.5              |
| Latinos with lower acculturation             | 34.8       | 24.3 – 45.3             |
| Latinos with high acculturation              | 41.7       | 10.9 – 72.4             |

Weights for probability of selection, non-response, and post-stratification were applied.

**Table 30**

**Odds ratio of being insured and confidence interval for Latinos in southwestern Pennsylvania, controlling for region and acculturation**

|   | Odds ratio | 95% Confidence interval |
|---|------------|-------------------------|
| Annual family income >=\$20,000         | 6.8        | 2.7 – 17.3              |
| Formal education: at least some college | 7.4        | 2.9 – 19.0              |

For a more complete result of regression, please see Appendix 10.

## 2. Regular source of care

In SWPA, the weighted proportion of Hispanic adults who do not have a regular source of care is 21.4% (95% confidence interval 13.9 - 31.3). This is not statistically different from findings for the U.S. from different national surveys during the last decade, although it is smaller than the percentage reported in 1987 (32.9%) (See Table 31).

**Table 31**

**Weighted percentage of Latinos in southwestern Pennsylvania without a regular source of care, compared to results of national surveys**

|   | Percentage |
|---|------------|
| Latinos in southwestern Pennsylvania 1998-1999 <sup>a</sup> | 22.6       |
| Latinos in the United States NHIS 1995-1996 <sup>b</sup>    | 26.0       |
| Latinos in the United States MEPS 1996 <sup>c</sup>         | 29.6       |
| Latinos in the United States NMES 1987 <sup>d</sup>         | 32.9       |

<sup>a</sup>Data were weighted for probability of selection, non-response, and post-stratification.

<sup>b</sup>Brown et al 2000, includes people between ages 18 and 65.

<sup>c</sup>Kass et al 1999, includes people of all ages.

<sup>d</sup>Schur and Albers 1996, includes people  $\geq 18$  years of age.

The percentage of Hispanic people without a regular source of care is not significantly different by income level or English proficiency. However, the proportion of Latinos with no regular source of care is significantly higher among those with low acculturation than among those with high acculturation.

**Table 32**

**Weighted percentage of Latinos in southwestern Pennsylvania without a regular source of care, by income, English proficiency and acculturation**  
**Weighted estimates and confidence intervals**

|  | Percentage | 95% Confidence interval |
|--|------------|-------------------------|
| All  | 22.6       | 13.9 – 31.3             |
| Latinos with annual family income <\$20,000  | 34.6       | 14.7 – 54.5             |
| Latinos with annual family income >=\$20,000 | 10.8       | 4.6 – 16.9              |
| Latinos with lower English proficiency       | 28.6       | 14.0 – 43.2             |
| Latinos with high English proficiency        | 14.1       | 3.4 – 24.9              |
| Latinos with lower acculturation             | 34.3       | 24.0 – 44.7             |
| Latinos with high acculturation              | 9.6        | 0.0 – 19.2              |

Weights for probability of selection, non-response, and post-stratification were applied.

Logistic regression shows that people who have health insurance are five times as likely to have a regular source of care as those who were uninsured. It also shows that those who have been in the U.S. for 5 years or more, are six times as likely to have a regular source of care as those who have been here less time (Table 33). Income and acculturation were not significant determinants of having a regular source of care, when data were controlled for insurance status, time in the U.S., sex, and education. However, they did have a significant effect in the univariate regression. From the results, it may be inferred that the effect of income on regular source of care is exercised through insurance status. This makes theoretical sense, and is consistent with the findings of logistic regression regarding insurance status, as described earlier, where income was a main determinant. In the case of acculturation, it appears that the effect is exercised with time in the U.S. This also makes sense, as time in the U.S. is one of the major determinants of acculturation level, according to Negy and Woods (1992). Education and sex were important in determining the

effect of other variables in the equation, but the odds ratios were not different from zero. Additionally, a negative interaction between insurance status and time in the U.S., indicates that insurance status might be determining source of care differently for people who have been in the U.S. for 5 years or more than for those who have been here less time. Income makes a greater difference (a steeper curve) for those that have been in the U.S. for less than 5 years than for those who have been here for longer. People who are in the U.S. for a short time are unlikely to be naturalized or to know the different options within the system. For them, income is the only means to attain a regular source of care.

**Table 33**  
**Odds ratio of having a regular source of care, and confidence interval for Latinos in southwestern Pennsylvania, controlling for income, acculturation, education, time in the U.S., and sex**

|                                  | Odds ratio | 95% Confidence interval |
|----------------------------------|------------|-------------------------|
| Time in the U.S. 5 years or more | 4.6        | 1.7 - 12.8              |
| Health insurance present         | 5.8        | 2.1 - 16.0              |

For a more complete result of regression, please see Appendix 10.

***C. Factors that affect potential access to health services: social and economic conditions***

The literature mentions several important factors that affect the ability of an individual to obtain health insurance: country of origin, income, education, type of job, time in the U.S., age, and legal status (Brown et al, 2000; de la Torre et al, 1999; Kass et al, 1999; Thamer et al, 1999). Furthermore, these factors are frequently interrelated. I will now explore these results in light of findings from national studies and the qualitative data gathered in this research.

## 1. Income

Study findings for SWPA agree with national data that indicate socioeconomic factors are the most important determinants of health insurance status, as well as access to health care in general. Giachello (1996 b) contends that, at the national level, income is unequivocally the heaviest determinant of insurance status. De la Torre et al (1999) has analyzed data from the Hispanic Health and Nutrition Examination Survey (HHANES) to show that, among older Latinas, family income, employment status and education are determinants of health insurance. Burciaga-Valdez et al (1993) has studied CPS data from 1980 and 1990 and found that the main determinants of insurance status were annual family income, educational level and job status. Perhaps the most important way in which income affects health insurance status is that higher income jobs usually offer fringe benefits, such as health insurance. These same jobs are the ones that require more years of formal schooling. Additionally, people with higher incomes are more able buy insurance, even if their job does not offer it, or they are self-employed.

In SWPA, a few people with whom I spoke bought on their own private insurance, and these people had a relatively high income. Some older professionals I spoke with had not had formal insurance per se in the past, but their employers paid all the costs of medical care for workers and their families. However, only one interviewee still had that type of coverage. Today, most of those professionals have reasonably generous insurance plans, though they are not as generous as their previous arrangements. They have fewer options from which to choose their providers than in the past. These changes reflect changes in the country's health care system that affect all people in the U.S.

## 2. Jobs and education

The other variable that shows significant effect on insurance status in these data is formal education. It is quite possible that education reflects different job status among Latinos, as found by Brown et al (2000), Brown et al (1999), HRSA (1999), and Kass et al (1999). Not everybody working in SWPA has an option for health insurance. Hispanics in general do not have access to

the best paying jobs, and an individual with fewer years of formal schooling had less chance of working in a stable job offering benefits. According to this data, 128 of the 160 surveyed Latinos with health insurance are insured through their own or someone else's job. Often, people I spoke with held jobs that were unstable, paid a lower salary, or were in the service or informal sectors. These people were not offered insurance through their jobs. It is important to note this phenomenon does not seem to be related to immigration status; it happened even to workers born in the U.S.

Even if all jobs offered health insurance, this may not solve all problems related to health care access, as realized by Giachello (1996 b). Although many Hispanics in SWPA do get jobs offering insurance, the waiting period before it would become active lasts anywhere from two weeks to several months. For workers, such as Rita, a full time employee in the service sector, the waiting period was one year. Although she complained of pain in her knees and back, she had yet to see a doctor. She hoped to be able to continue working eight more months, until she could get covered care. Some informants reported alternating between being employed and being out of work. They also alternated between being insured and uninsured. The waiting period for the insurance plan to be operational, plus the high turnover in jobs resulted in many people being uninsured most of the time, even when they worked at jobs with benefits.

Another limitation of some insurance plans offered by jobs in SWPA is failure to cover the whole family. I found several examples of this. In one family, a woman was insured through her husband's job, but their children were not. In another family, the father and children were covered through his job, but the mother was not. Students, for the most part, only had access to student health services. The scope and quality of those services were often matters of concern for users. Some students had children and/or spouses; they were usually not insured.

Finally, several subjects mentioned that their job-related insurance plans did not cover prescription medicines, did not pay for specialist visits, required steep co-payments, or offered few choices of providers. Some insurance plans covered treatment for some diseases, but not for all. For example, one woman mentioned that her plan did not cover the pills for *nervios* (nerves) her doctor

had prescribed. For these reasons, many found health care expensive, even when they had health insurance.

Apparently, most jobs cover treatment for work-related injuries, at least treatment for the acute episode. Some agricultural workers in Washington County and some unskilled workers in urban areas told me that they had been treated at the company's expense when they were injured on the job. I could not find any evidence of coverage or lack thereof for sequelae of job accidents. In some cases, however, people were not covered, nor were they protected from injuries. For example, Roger, a 16-year-old Mexican youth, had been working in agriculture in a different state. He came to the Pittsburgh area because he felt weak and had some family friends here. Roger tried to "help" at a local restaurant, but he had to stop, due to his illness. He was uninsured and could not afford to pay for care. His friends cared for him at home. Roger's condition deteriorated, and he was eventually hospitalized through the emergency room. Many days later, he died. Following his death, a young man who had been working on the farm with Roger, arrived in Pittsburgh. He told the family that Roger had been spraying insecticides without proper protection. His death was likely caused by toxic exposure to the insecticides.

Other ways in which income affects health insurance, or health insurance affects income, were exemplified by the following stories. Luisa received disability income. She had health insurance, but would lose it if she worked. Even though she could have performed some minor tasks to supplement her income, she did not, because she feared losing her main source of income (about \$500 a month) and, more importantly, her insurance. Others, in the same situation as Luisa, took the risk and did some cleaning or babysitting. Marcela, a disabled woman in her thirties was quite happy with her Medicare coverage. She had gotten several operations, and everything had been covered. However, she had a family to support and needed more income. She worked as a cleaning person in two jobs, one by day, one by night. I learned by accident, from a provider, that Marcela could not keep up with her health-related appointments because of her complicated work schedule. This, coupled with the extra physical stress of two jobs, made her health care much more difficult to manage and her health status more uncertain. The Pérez family also

faced problems in health care. They came to Pittsburgh because the father needed a transplant. However, in just a few months, they had used up all his insurance allocation and had to go on welfare. He then received care through Medical Assistance, but his wife remained uninsured. She did not work outside the home, due to her husband's poor health and need for constant assistance. She hoped to be strong enough to stay healthy, since she would not qualify for Medicare for another 10 years.

A few informants who were not U.S. citizens told me they had insurance in their country of origin. Medical services here were usually covered, to a certain extent, but unless it was an emergency, they received care in their own country. Others who came temporarily to the United States had insurance through their credit card. These options, have also been described by Burciaga Valdez et al (1993) and de La Torre et al (1999); they are limited to those with relatively high income and/or require complicated arrangements involving international travel.

Data from the survey indicate that 1 of 25 children had some type of health insurance, but only 14 of 25 (56%) obtained health insurance through a parent's job. Four children received medical assistance, and 6 received an "other" type of insurance. Some parents, who were not interviewed, told me during informal conversations that their children were enrolled in CHIP, MA or Medicaid. These plans are an option for children of uninsured parents and those parents whose insurance cannot be extended to cover children. Some Latinos' children just had athletic insurance through the school. This covered only accidents that happened while the child was on school property. Young people in college might have insurance through their parents' jobs or paid by them. Again, this was related to family income. At the national level, Latinos earn little money, but they tend to be in families with working parents. Even when two parents work, it can be difficult to purchase insurance, yet they do not qualify for Medical Assistance, as stated by Halfon et al (1997) and Brown et al (1999). The same was observed among SWPA Latinos.

Only four Latinos surveyed in SWPA reported having insurance through Medicare. Two of them purchased "Medigap" to cover those things Medicare did not cover. However, it is not rare to find people who were almost 65 and have no

insurance. I discussed this with at least three individuals, who had been delaying their periodic medical exams. They were waiting to reach the age they will become eligible for Medicare to resume their checkups. For the time being, they hoped to keep healthy. Many elderly people who were not citizens or permanent residents did not have insurance and had no hope of qualifying for Medicare. This was the case of Camila's mother, who was older than eighty and spends 8 to 9 months a year in the U.S. Although Camila has an annual income of more than \$50,000, she still has trouble paying for her mother's health care needs.

During participant observation, some Latinos told me that they did not have a source of care because they work long hours, making it almost impossible to arrange health care. This problem is most common among service sector workers, who typically hold more than one job, but it was not exclusive of them. For example, a physician, who had no source of care solved his health problems by talking with his friend in the hospital hallway. Five years had passed and he had not undergone a routine medical exam.

### 3. Health insurance

Many Latinos in SWPA believe the main problem with access to care is lack of insurance for all, stemming from poor economic conditions. Many poor and middle class Latinos said that health care was outrageously expensive. If all jobs offered insurance, many interviewees said, there would be no problem. Results from a study in San Diego and Dallas (Chavez et al, 1992) support this finding. Using logistic regression they show that uninsured Latinos are 3 times more likely to have never sought care than those with insurance. However, even if every person who had a job were insured the undocumented would always be at risk, unless there were health coverage for everybody, such as would be provided by a national health system.

Some Hispanics in SWPA had Medicaid or some sort of Medical assistance. However, just four of the people surveyed reported having public insurance. A small number was expected, perhaps because of immigration status. This happens in other areas, such as in Texas, where few have public insurance (Chavez et al, 1992). Only U.S. citizens, and sometimes permanent

residents, qualify for most public insurance options. Even when the latter is true, there are few indications of an increase in the number of Hispanics who use medical assistance in SWPA. For example, one person reported that he had been offered a position at a firm that was paid to ensure that families in MA received all the preventive care they should receive. They wanted a fully English-Spanish bilingual person to work as a case manager for the Pittsburgh area. This job opening might reflect a local need. Additionally, a few people, who otherwise did not qualify for Medicaid, might get an “emergency Medicaid” option, a once in a lifetime payment of their hospitalization bill.

Nationally, as in our sample, having insurance is an important determinant of having a regular source of care for both adults (Brown et al, 2000) and children (Brown et al, 1999; Smith et al, 1996). In McFarland, CA, Smith et al (1996) found that not having insurance, having only public insurance, and living with a Spanish only speaking family were predictors of not having a regular source of care for children. In this research, only 2 of 25 Hispanic children did not have a regular source of care.

#### ***D. Factors that affect potential access to health services: misconceptions, miscommunication, language and culture***

##### 1. Misconceptions and misinformation

Some affluent people, including some Latino health providers with whom I spoke, believe there are no health care access problems for Latinos in SWPA or, even in the U.S. They are convinced that everybody is covered in some way, that everybody who has a job is insured and that those who are very poor receive charity care. They believe this to be true for emergencies as well as for regular care. According to them, only “illegal aliens” might have insurance problems. They regard the fact that some people have an uncertain immigration status as a negative trait of the person; their status is their fault, and they would have fared better if they had never tried to enter this country in such a way. This kind of blaming the victim was not rare. It reflects the class division in this population, one of the factors that precludes Latinos in SWPA from

organizing to protect their interests. It also points to the lack of current information on health insurance of some Latino health providers in the area.

Other providers in the area believe that there are plenty of opportunities to get health insurance, but that many are missed because of lack of information and/or spread of misinformation. The survey used in this research did not measure information about insurance options. However, I was able to confirm that misinformation was widespread when talking with those who were uninsured. For example, many did not know their children would qualify for CHIP. Many did not know the options that existed, and there was no widely available Spanish-language literature about those options, much less information that was culturally acceptable, as one physician pointed out. Many Latinos, during interviews and participant observation, asked me for a referral, information about how to get health insurance or otherwise affordable care. Since I really could not help them directly, I referred all inquiries to the contact person in Family Resources (FR) who works for the *Programa para la Familia Latina*. In this sense, FR had been raising awareness in the community about services that were available at low or no cost and options for which people might qualify. The *Programa para la Familia Latina* was good, but understaffed. Additionally, it was difficult for FR to reach a community that was loosely organized and geographically scattered.

Even when Latinos were insured, they might not be able to take full advantage of their insurance plan, due to misinformation and cultural barriers. In SWPA, the uninsured tended to feel they were discriminated against by the health care system; as a result they sought treatment only in an emergency. Some said that as soon as the administrative health care staff perceived them to have an accent, the focus shifted from their ailment and its treatment to questions of whether or not they had insurance.

## 2. Language and culture

Some people do not get enough information because they do not speak English. This has been reported in the literature. For example, a study at the University of Pittsburgh, by Lin et al (cited by the University of Pittsburgh Schools of the Health Sciences' News Bureau 1999) found that 75% of Hispanic

children who were eligible for but not enrolled in Medicaid had parents who were interviewed in Spanish and had a low understanding of the enrollment procedure. Misinformation not only hurt those who were not proficient in English, Wendy's story illustrates. Wendy was a homemaker, and her husband was a painter. He used to be unionized, and they had access to health care coverage. However, he was now independent and he could not afford to buy insurance. Paying medical bills was a problem, especially during the winter, when he could do almost no work. A social worker told Wendy that her school age children did not qualify for CHIP, when in reality they did. In this case, at least, language proficiency was not a problem, because Wendy was a Pennsylvania native and English monolingual speaker of Mexican origin.

Acculturation did not prove to be a significant determinant of insurance status in SWPA. However, we have to remember that the acculturation variable reflects only those dimensions of culture that compose the scale. Chavez et al (1992) found in Texas and California that after a median of nine years, immigrants learn how to use the system and/or acquire jobs that provide health insurance. Nationally, time of residence in the U.S. is an important determinant of insurance status (Thamer, 1997). People who have been here for more time are more likely to have found a stable job offering benefits. Others have had more time to work out their immigration status, learn English and learn how the U.S. health system works. All of these factors may affect their ability to find health insurance. Our survey findings did not confirm this; perhaps time in the U.S. was not a significant determinant of insurance status for Latinos in SWPA. Another explanation might be that the sample was small.

Even though acculturation was not a significant determinant of having a regular source of care in a multivariate setting, it appeared to act together with time in the U.S. and to have an effect independent of insurance status. Time in the U.S. was likely to change many culturally related attitudes and beliefs. Even though time in the U.S. was not a question of the acculturation scale, the dimensions used to measure acculturation may depend heavily on it. Other studies have found a relationship between time of residence in the U.S. and regular source of care. From a survey of school students in New York City, Sonis (1998) found that there was a statistically significant trend for students

who were in the U.S. for longer periods of them to have a regular source of routine care and a regular source of illness care.

Some details people mentioned during informal conversations could be considered culturally related. For some Latinos in our area, health insurance is a new concept, and they do not fully understand what it is. For example, one man said that he was healthy, but that if he got sick, he would try to find a hospital that had “an insurance” for him. In other cases, people do not understand how to get the actual care, they consider the procedure too complicated, or they did not know how it worked. They also feel it is complicated to understand who qualifies for what. Other people told me that they extremely dislike paperwork, especially in relation to health care. They receive bills for what they did not use, bills for the wrong amount, bills asking for payment they had already submitted, or papers that were not bills, but looked like them. All of this made the system more complicated to understand and negotiate, especially for those with fewer years of formal schooling and insufficient command of English. An article in the *New York Times* (Kilborn, 1999) cites health care providers who believe that health insurance is a foreign notion for Latinos and that paperwork is too complicated for them. According to Schur and Albers (1996), other cultural factors might include distrust of health providers, lack of acculturation, and differences in health beliefs.

Some people in SWPA report they have an “assigned” regular source of care, which they had never used. They do not know their doctors and plan to go only if they become sick. It is questionable how “regular” this source of care is. Twenty-seven of the forty-four surveyed individuals with no regular source of care, said they did not have a source of care because they had not needed a doctor. Some people were unhappy with their current source of care, but they had no choice and stayed with the assigned physician. Latinos who felt discriminated against or treated unfairly, and those who believed their doctor was incompetent or too cold, changed their doctors when possible. At least five individuals told me they had changed doctors for these reasons. However, none of them told the provider or the insurance company why they were switching doctors.

According to Solis et al (1990), the type of source of care chosen depends on the constraints the person faces, but also on his or her culture. Schensul and Schensul (1982) add that extensive use of home care to delay seeking professional services can result in people going to the emergency room when they are very sick. Use of the emergency room as a usual source of care is expensive and leads to low quality care, due to lack of continuity (Schensul & Schensul, 1982; Riedel, 1998). In this research, very few people mentioned the emergency room as their regular source of care. Those who did so reported going infrequently. People felt they were not treated in the best way. For example, Genaro said that he used to go to the emergency room for all his health care needs, because he had no choice. It was open 24 hours a day, and his work made it difficult to schedule appointments. However, he disliked it because the care providers did not understand his concerns. One time he had a high fever and felt very sick. He had to wait a long time before seeing a doctor. Finally, three different people examined him. They charged him \$80, and he walked out feeling just as bad, with no medicine and a diagnosis of “nothing.” Genaro felt cheated and has tried to avoid going to doctors since that episode. Much has been said about excessive emergency room use by Latinos (Cornelius, 1997; Riedel, 1998; Schensul & Schensul, 1982), but it appears that it is actually not as important in SWPA, although data gathered were insufficient for drawing any meaningful conclusions. However, it would agree with the findings of Chavez et al (1992) in Dallas and San Diego. There, in 1986, between 6.4 and 19.5% of the health care visits were to emergency rooms, including many maternity visits. They found that use of clinics was much more frequent than use of emergency rooms and that Latinos tended to use services that were cost-effective for them. Those services tended to be the ones that were most cost-effective for the nation, too.

Some of those in SWPA who had an informal source of care did not want to disclose whom they saw or where they went for health care. It is possible that they used an informal arrangement or a type of doctor outside of the regular medical system, such as *curanderos*. However, I could neither confirm nor reject this hypothesis.

### ***E. Country of origin and immigration status***

Nationally, country of origin is an important determinant of insurance status, at least during the first years immigrants spend in the U.S. It is related to age group and type of job. Puerto Ricans, as U.S. citizens, may have access to the most health care services and insurance plans. If they are employed, their immigration is always legal. They qualify for Medicare when they reach the appropriate age or have a disability. If they meet the income requirements, they can enroll in Medicaid. However, not all Puerto Ricans in SWPA are insured. In talking informally with Puerto Ricans in our area I found that several of them were working and did not qualify for Medicaid, but could not afford to buy insurance. This is the situation for millions of other U.S. citizens. Refugees are also a special case. I met several Cuban refugees that came to the U.S., about 5 or 6 years ago. They said they received assistance with health care during the first months after their arrival, but later they had to procure their own insurance. They did not qualify for Medicaid, and some of them have had difficulty finding a job that offers insurance right away, because they need to learn the language and/or they needed to be retrained to have marketable skills. In SWPA, country of birth showed significant influence on health insurance status, but the odds ratio was not different from zero. The reason might be that most of the cases in which a clear positive difference in insurance status by region of birth can be observed correspond to Puerto Ricans and refugees, who are mostly Cuban and Central Americans. The number of sampled subjects in those groups was so small that Cubans and Central Americans were combined into one group with "Others". "Others" included individuals born in Cuba, Puerto Rico, Central America and the United States. Another country from which there are many refugees in the U.S. is Colombia, and this country was put together with the rest of South America.

Some interviewees told me that they knew people from other countries who migrated without a visa and did not have access to insurance. In SWPA, the issue of immigration status might be just as important, but it was purposely not explored. However, one may surmise that people who have an uncertain immigration status in the U.S. face the most difficulties in obtaining

health insurance. Vega and Amaro (1994) say one of the reasons Latinos are less likely to be insured is that they are more frequently undocumented or seasonal workers. Most immigrants that came to the U.S. with a visa did not qualify for Medicare or could not get Medicaid, unless they have become naturalized citizens. As reported by several individuals in SWPA, naturalization was a process that took several, and in some cases, many years. Nationally, Mexicans are less frequently insured than Cubans and Puerto Ricans (Burciaga Valdez et al, 1993; de la Torre et al, 1999; Solis et al, 1990).

### ***F. Summary***

In SWPA, 38.1% of Latinos do not have any health insurance, and 21.4% have no usual source of care. These proportions are similar to those for Latinos at the national level, in spite of the high proportion of Latinos in SWPA who have at least some college education. However, in the social context chapter, income for Latinos was found to be low relative to years of education. One of the main ways in which income affects insurance status is the type of job. Not all jobs offer health insurance. Some do, but there might be some obstacles. Sometimes there is a long waiting period between the employment date and the date health coverage is initiated. Often, not all types of health services are covered and members of the family might even be excluded. This situation exists because the jobs of Latinos tend to be unstable, temporary, and/or low paying. The reasons are diverse, but they include lack of English proficiency, certification issues, and immigration problems.

In the multivariate analysis, socioeconomic factors were strong determinants of potential access, pointing to inequitable access to care. Specifically, income and education are independently significant predictors of having health insurance. Those with annual family incomes of \$20,000 or more and those who have at least some college education, are about seven times more likely to be insured than those with less income or fewer years of education. Hispanics with health insurance are significantly more likely to have a regular source of care than those who do not have insurance. Income influences source of care through insurance status. An additional variable that

proved to significantly affect having a source of care is time in the U.S. For Latinos who have spent five years or more in the U.S., income makes a smaller difference in obtaining a source of care. This is because after several years their immigration status might have stabilized, they may access options for citizens, they might hold a job that offers insurance as a benefit, and/or they might have learned how to use the various options for care in the U.S.

Acculturation was a significant predictor of having a regular source of care in the univariate analysis, but its effect disappeared after introducing the variable “time in the U.S.” The reason might be that most of the dimensions used to measure acculturation are affected by time of permanency in the U.S.

Cultural issues appeared to be of less importance than financial ones in determining potential access to health care, although qualitative data showed that there was a great deal of misinformation about health care options. Often Latinos do not know the options available or do not understand how health insurance works. This happens partly because of language incompatibility, partly because of absence of culturally appropriate materials, and partly because of the socioeconomic divide within the Latino population of SWPA. Those Latinos in the health system who could help to educate or inform the more socioeconomically disadvantaged Latinos, do not consider it important to do so.

The literature mentions that Latinos overuse emergency departments. In the data, there was no evidence of this. However, the issue was not thoroughly studied, and further research may be warranted. Although not directly studied, immigration status was likely to play a major role in ability to obtain health insurance and the perception individuals had of their own rights and safety.

## **VII. Realized access to health care**

### ***A. Introduction***

Realized access to health care refers both to care actually received and to the evaluation users give of that care. Realized access to health care can be both preventive and curative. Preventive care includes not only personal services (i.e., immunizations, mammography) but also health education. It is important for three reasons. First, it contributes to the maintenance of peoples health. Second, it significantly contributes to lower health care costs, as preventive care is less expensive than curative care. Third, and perhaps most importantly, prevention reduces the cost of illness in human suffering and pain.

When I talk about realized access to care I am referring to preventive, curative, and restorative care. In the following pages, I will give a short description of the main survey findings on the variables measured. Later, I will attempt to integrate quantitative and qualitative information to elucidate the major constraints Latinos in SWPA face when accessing health care and how they are related. I will specifically explore financial factors (including income) and cultural factors (including language, views on health care, preferred relationships with providers and communalism). Finally, I will explain the effects of immigration status and discrimination on realized access to care.

## ***B. Utilization of health services and satisfaction***

### 1. Blood pressure measurement in the past year

Overall, the weighted proportion of Latinos in SWPA who have not had a blood pressure measurement in the past year was 20.9%. There were no statistical differences among the proportion of people who had a blood pressure measurement in the past year by income or English proficiency. However, those with lower acculturation were significantly more likely to have not had a blood pressure measurement in the past year than those more acculturated.

**Table 34**

**Weighted percentage of Latinos in southwestern Pennsylvania who did not have a blood pressure measurement in the past year by income, English proficiency and acculturation. Weighted estimates and confidence intervals**

|  | Percentage (95% Confidence interval) |             |
|--|--------------------------------------|-------------|
| All  | 20.9                                 | 12.4 – 29.4 |
| Latinos with annual family income <\$20,000  | 26.7                                 | 10.2 – 43.3 |
| Latinos with annual family income >=\$20,000 | 15.2                                 | 6.4 – 24.0  |
| Latinos with lower English proficiency       | 22.5                                 | 10.2 – 34.8 |
| Latinos with high English proficiency        | 18.7                                 | 6.5 – 30.8  |
| Latinos with lower acculturation             | 31.1                                 | 20.5 – 41.6 |
| <u>Latinos with high acculturation</u>       | 9.7                                  | 0.3 – 19.1  |

Weights for probability of selection, non-response, and post-stratification were applied.

### 2. Children's immunizations

All 25 sampled children had received the polio vaccine. Only one to three children had incomplete doses of each of the other four vaccines (MMR, DPT, Hepatitis B, and Haemophilus type B). Six children had not received the chickenpox vaccine, which was not surprising, since it was a rather new vaccine.

### 3. Visit to the doctor in the past year

The weighted percentage of Latinos in SWPA who have not had a doctor's visit in the past year was 20.2%, similar to that found recently at the national level. Of the 25 children in the sample, only one had not visited to the doctor in the past year.

**Table 35**

**Weighted percentage of Latinos in southwestern Pennsylvania who had no visit to the doctor in the past year, compared to results of national surveys**

|   | Percentage |
|---|------------|
| Latinos in southwestern Pennsylvania 1998-1999 <sup>a</sup> | 20.2       |
| Latinos in the United States NHIS 1994-1995 <sup>b</sup>    | 17.0       |
| Latinos in the United States NHIS 1992-1995 <sup>c</sup>    | 27.3       |

<sup>a</sup> Data were weighted for probability of selection, non-response, and post-stratification.

<sup>b</sup> HRSA 1999, includes people between ages 18 and 65.

<sup>c</sup> Hajat et al 2000, includes people of all ages.

There is no statistically significant difference in the proportion of Latinos who did not see a doctor in the past year by income, English proficiency, or acculturation. The last time they went to the doctor, 68 of the 204 interviewees who responded the question (33%) had a preventive visit. Sixty-six went for a checkup and two for pre or post-natal care.

**Table 36****Weighted percentage of Latinos in southwestern Pennsylvania who did not see a doctor in the past year by income, English proficiency and acculturation**  
**Weighted estimates and confidence intervals**

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|  | Percentage | 95% Confidence interval |
|--|------------|-------------------------|
| All  | 20.2       | 11.9 – 28.6             |
| Latinos with annual family income <\$20,000  | 22.2       | 7.5 – 37.0              |
| Latinos with annual family income >=\$20,000 | 18.3       | 8.9 – 27.7              |
| Latinos with lower English proficiency       | 19.7       | 8.9 – 33.2              |
| Latinos with high English proficiency        | 21.0       | 16.7 – 42.4             |
| Latinos with lower acculturation             | 26.1       | 15.9 – 36.2             |
| Latinos with high acculturation              | 13.8       | 2.3 –25.2               |

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Weights for probability of selection, non-response, and post-stratification were applied.

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Income and acculturation were not important determinants of having visited the doctor in the past year, according to results of multivariate logistic regression. However, women were six times more likely than men to have seen a doctor in the past year, as is generally reported for all populations. Aday et al (1998) say that women see doctors more frequently because of childbearing, longevity, and greater societal acceptance. Those who have a regular source of care are almost seven times more likely to have seen a doctor in the past year than those who do not have a regular source of care. Insurance status determined whether or not an individual had a visit to the doctor in the past year by determining that the individual have a source of care.

**Table 37**

**Odds ratio of having a visit to the doctor in the past year, while controlling for income, acculturation and insurance status, and confidence interval for Latinos in southwestern Pennsylvania**

|                         | Odds Ratio | 95% Confidence interval |
|-------------------------|------------|-------------------------|
| Sex (being female)      | 6.14       | 2.28 - 16.52            |
| Having a source of care | 6.73       | 2.35 - 19.32            |

For a more complete result of logistic regression, please see Appendix 10.

**4. Visit to the dentist in the past year**

Close to 33% of Latinos in SWPA did not see a dentist in the past year. The last time they went to the dentist, 106 of the 205 interviewees who responded to the question (51.7%) went for a cleaning or a checkup. National data on dental visits in the past year were not available, but data from other areas in the U.S. with larger Latino populations show that Hispanics elsewhere see a dentist with less frequency than Latinos in SWPA.

There was no statistically significant difference in the proportion of Latinos who did not see a dentist in the past year by income, acculturation, or English proficiency. However, the estimates on acculturation were almost different. Results from multivariate logistic regression did not show a statistically significant effect of income or acculturation on having a visit to the dentist. As a matter of fact, the only variable that was “borderline” significant was having a regular source of care. The probability of the difference being the result of chance was exactly 0.05. It is likely that this result was affected by the small sample size.

**Table 38****Weighted percentage of Latinos in southwestern Pennsylvania who had no visit to the dentist in the past year, compared to results surveys in other areas of the U.S.**

|   | Percentage |
|---|------------|
| Latinos in southwestern Pennsylvania 1998-1999 <sup>a</sup> | 33.0       |
| Collaborative Study of Oral Health Outcomes, 1990-1991      | 57.8       |

<sup>a</sup> Data were weighted for probability of selection, non-response, and post-stratification.

<sup>b</sup> Davidson et al 1996. Data are from San Antonio, TX, Baltimore, MD, and two Indian Health service sites. Includes people ages 35 to 44, dentate.

**Table 39****Weighted percentage of Latinos in southwestern Pennsylvania who did not see a dentist in the past year by income, English proficiency and acculturation**  
**Weighted estimates and confidence intervals**

|  | Percentage | 95% Confidence Interval |
|--|------------|-------------------------|
| All  | 33.0       | 22.1 – 43.8             |
| Latinos with annual family income <\$20,000  | 40.7       | 18.4 – 63.0             |
| Latinos with annual family income >=\$20,000 | 25.4       | 15.7 – 35.2             |
| Latinos with lower English proficiency       | 35.5       | 18.4 – 52.5             |
| Latinos with high English proficiency        | 29.5       | 16.7 – 42.4             |
| Latinos with lower acculturation             | 44.5       | 33.7 – 55.3             |
| Latinos with high acculturation              | 20.3       | 6.2 – 34.3              |

Weights for probability of selection, non-response, and post-stratification were applied.

**Table 40**

**Odds ratio of having a visit to the dentist in the past year, while controlling for income, acculturation, education, sex, region of birth, and insurance status, and confidence interval for Latinos in southwestern Pennsylvania**

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|                         | Odds ratio | 95% Confidence interval |
|-------------------------|------------|-------------------------|
| Having a source of care | 2.39       | 0.99 - 5.77             |

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For a more complete result of logistic regression, please see Appendix.

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### 5. Satisfaction with health services

In this study, 21.9% of Latinos were, in general, “moderately” or “not at all” satisfied with the care they received. There were no significant differences by income, English proficiency or acculturation. During informal conversations, most Latinos who did obtain care said they were quite happy with it. This was true of people with private insurance, those with public coverage, and even some with no insurance at all.

Results of multivariate logistic regression showed that neither income nor acculturation was an important determinant of satisfaction with services received. The only variable that proved to influence satisfaction significantly was educational level. Latinos that had formal education of at least some college were significantly less likely to be satisfied with care than those with less formal schooling.

**Table 41**

**Weighted percentage of Latinos in southwestern Pennsylvania who were “Moderately” or “Not at All” satisfied with care received by income, English proficiency and acculturation. Weighted estimates and confidence intervals**

|  | Percentage | 95% Confidence interval |
|--|------------|-------------------------|
| All  | 21.9       | 13.7 – 30.1             |
| Latinos with annual family income <\$20,000  | 18.7       | 5.4 – 31.9              |
| Latinos with annual family income >=\$20,000 | 24.8       | 16.7 –33.0              |
| Latinos with lower English proficiency       | 22.2       | 9.4 – 35.0              |
| Latinos with high English proficiency        | 21.4       | 12.2 – 30.6             |
| Latinos with lower acculturation             | 29.6       | 19.6 – 39.7             |
| Latinos with high acculturation              | 14.1       | 4.4 - 23.7              |

Weights for probability of selection, non-response, and post-stratification were applied.

**Table 42**

**Odds ratio of being satisfied with medical care, while controlling for income, acculturation and having a source of care, and confidence interval for Latinos in southwestern Pennsylvania**

|                                  | Odds ratio | 95% Confidence interval |
|----------------------------------|------------|-------------------------|
| Education: at least some college | 0.29       | 0.11 - 0.72             |

For a more complete result of regression, please see Appendix 10.

**Table 43****Percentages of Latinos “Moderately” or “Not at All” satisfied with several dimensions of health care. Comparison of data of southwestern Pennsylvania 1999-2000 and the U.S. 1982. Weighted estimates and confidence intervals**

|                               | Latinos in SWPA                 |               | Latinos in the          |
|-------------------------------|---------------------------------|---------------|-------------------------|
|                               | Estimates (Confidence Interval) |               | U.S., 1982 <sup>a</sup> |
| Time to get there             | 19.8                            | (11.7 – 27.8) | 29                      |
| Treatment by the receptionist | 15.6                            | (9.1 – 22.0)  | n.a.                    |
| Waiting time in the office    | 33.9                            | (22.4 – 44.7) | 37                      |
| Treatment by the doctor       | 9.7                             | (5.3 – 14.1)  | n.a.                    |
| Time with the doctor          | 17.9                            | (10.8 – 25.1) | 29                      |
| Information received          | 21.3                            | (13.3 – 29.3) | 25                      |
| Out of pocket cost            | 16.4                            | (9.5 – 23.4)  | 38                      |
| Quality of care               | 14.8                            | (8.4 – 21.1)  | 24                      |
| Language spoken               | 15.3                            | (8.6 – 22.1)  | n.a.                    |
| Satisfaction in general       | 21.9                            | (13.7 – 30.1) | 28                      |

Weights for probability of selection, non-response, and post-stratification were applied.

<sup>a</sup> Aday et al 1984.

Nine survey questions explored several dimensions of satisfaction with care. The dimension with which the largest proportion of people were “Moderately” or “Not at All” satisfied was time waiting in the office, followed by information received, time to get to the office and time spent with the doctor. Recent comparable national data were not found. Proportions of people who were “Moderately” and “Not at All Satisfied” with care in the 1982 National Access Survey (Aday et al, 1984) are shown in Table 43. The proportion of Latinos dissatisfied with waiting time in the office is larger in the national data, and the proportion of those dissatisfied with out-of-pocket cost was much higher across the nation than in SWPA. However, the proportion of those who were “moderately” or “not at all” satisfied in general was similar in both cases. The 1982 study did not explore language spoken, treatment by the receptionist, or treatment by the doctor.

## 6. Difficulties in Obtaining Health Care

Fourteen survey questions asked whether a series of situations posed a difficulty for the interviewee in obtaining health care at any point in his/her life in the U.S. The most frequently cited difficulty to obtaining care was long waiting times to get an appointment. Among the next five most frequent items, two were related to financial difficulties (“too expensive,” and “would lose salary if I missed work”), two were related to language and culture (“staff did not speak Spanish” and “there were no Hispanic employees”), and one was related to orientation (“did not know how to get there”).

Many Latinos said during informal conversations that they faced problems with the health system that could not be attributed to discrimination or differences in culture. The most frequently cited problem was long in-office waiting times. Another common problem was lack of flexibility in scheduling, and appointments that were too delayed to be useful for an acute episode. For example, a person with a sore throat might have been given an appointment for a date two weeks later. After such time, the medical encounter is likely to be irrelevant. Only a few patients believed that they were given appointments at a later date because they were Latinos. Several patients felt that it was too difficult to reach a specialist. Waiting times are one of the most often mentioned barriers to health care, not only among Latinos, but among any other group (Aday et al, 1984; Flores et al, 1998).

**Table 44****Percentage of Latinos in SWPA who answered that they had a particular difficulty when they tried to obtain health care in the U.S.****Weighted estimates and confidence intervals**

| Difficulty                            | Latinos in SWPA                 |               |
|---------------------------------------|---------------------------------|---------------|
|                                       | Estimates (Confidence Interval) |               |
| Care was not available when needed    | 12.3                            | (6.5 – 18.0)  |
| Too Expensive                         | 26.3                            | (16.1 – 36.6) |
| Did not know where to go              | 19.2                            | (11.4 – 27.0) |
| Did not know how to get there         | 23.3                            | (3.1 – 43.6)  |
| The schedule was not convenient       | 18.2                            | (11.0 – 25.4) |
| Waited too much to get an appointment | 32.0                            | (21.2 – 42.9) |
| Needed child care                     | 9.02                            | (4.1 – 13.9)  |
| Would lose salary if missed work      | 22.7                            | (13.3 – 32.0) |
| Waited too long in the office         | 15.3                            | (8.6 – 22.1)  |
| Staff was disrespectful               | 11.9                            | (6.3 – 17.5)  |
| Did not trust the staff               | 17.4                            | (10.2 – 24.6) |
| Staff did not understand concerns     | 15.4                            | (8.9 – 22.0)  |
| Staff did not speak Spanish           | 22.8                            | (14.1 – 31.6) |
| There were no Hispanic employees      | 22.2                            | (13.6 – 30.7) |

Weights for probability of selection, non-response, and post-stratification were applied.

***C. Factors that affect utilization of health services: income***

In this research, quantitative data showed that income is important for health care access to the extent it is necessary to obtain health insurance. Income determines health insurance status, which in turn determines having a regular source of care. This is in concordance with current theory, as is the fact that having a source of care determines having had a visit to the doctor. However, it is puzzling that income shows no effect on having had a visit to the doctor, not even in the univariate analysis. This is especially puzzling if we consider that 38% of the population in SWPA is uninsured, and thus have to

pay for their care. Perhaps this result might be explained by lower income people who are uninsured getting health care for free. In the next chapter I will explore possible ways in which this might have been achieved.

Income should be an important predictor of having had a visit to the dentist in the past year, too. This is especially true because insurance usually does not cover dental care. Consistent with this, the effect of income on having had a visit to the dentist was significant. However, the multivariate model showed it was not. Possible explanations for these findings include people avoiding care, getting subsidized care and getting care abroad. These options will also be explained in the next chapter. An alternative explanation is that income determined having a source of care, and source of care appeared to determine having a visit to the dentist. It is possible that the recommendation of providers at the usual source of care prompted subjects to seek dental care.

During participant observation many people told me they feel health care is too expensive. This agrees with the survey result that care being too expensive is a difficulty for 26% of interviewees. In the same way that there were financial disincentives to seeking care, there were also some financial incentives. For example, two service workers told me, in two separate conversations, that getting the flu vaccine was very important for them because they could not afford to get sick and miss work. By getting the vaccine they were trying to protect their income. This concern was also evident as almost 23% of survey respondents indicated that losing time at work represented a difficulty to obtain health care. It was likely that these difficulties affected more those who were self-employed or had a job that offered no benefits, because any time not worked was money not earned. Aday et al (1998) explain that income and insurance status are more likely to affect use of preventive services than curative ones, since there is no feeling of urgency about using preventive services. They add that having a regular source of care may influence an individual's decision to seek care.

The measurement of preventive service used in the survey, having had a blood pressure determination in the past year, proved to be not appropriate for capturing any differences in access. Therefore, most of the data presented were derived from participant observation. Although people mentioned income as an

important issue for medical care in general, not enough information about income as it affected preventive care was collected to make any assertions.

National and local studies in several areas of the U.S. have shown that once demographic variables are accounted for, the most significant influence on use of preventive services are education and/or income or health insurance status (Himmelstein & Woolhandler, 1995; Mark & Paramore, 1996; Martin et al, 1996; Napoles-Springer, 1996; Pearlman et al, 1996; Polednak, 1996; Riedel, 1998; Suarez, 1994; Treviño et al, 1996). In San Diego and Dallas, Chavez et al (1992) found that the most important barriers to obtaining health care were financial. In their study, uninsured individuals were three times more likely than insured ones to have never sought care. An interesting point of their study is that they did explore immigration status. Almost all of the undocumented immigrants who had health insurance sought health care. Treviño et al (1996) believe that universal health insurance would not take care of all the inequality in the use of preventive care. In fact, a study of a national Medicare beneficiary survey found that use of immunizations by the elderly was significantly related not only to primary insurance, but also to having supplemental insurance, having an HMO insurance, having a usual source of care, and being satisfied with care received (Mark & Paramore, 1996). Himmelstein and Woolhandler (1995) found that those who lived in rural areas or were poor were less likely to have used preventive services. In their sample, the uninsured were less likely to obtain care. However, 75% of those who did not seek care were insured, and those with Medicaid were more likely to have used preventive services. It is likely that the financial problem for the uninsured and the copayment for the privately insured are barriers to preventive services. Therefore, the important factor is not only insurance status, but also type of benefits offered by the insurance plan.

Other income-related barriers to realized health care are lack of child care, lack of transportation and release from work (Napoles-Springer et al, 1996). This study did not measure continuity of care in SWPA, but Cornelius (1997), analyzed 1987 NMES data and concluded that income and insurance are among the most important factors in determining continuity of care for Latino and African American patients across the nation.

#### ***D. Factors that affect utilization of health services: culture***

There is debate about whether cultural factors themselves play a role in access to health care or they are just markers of socioeconomic status. Halfon et al (1997) conducted a survey of Latino households with children in South Central Los Angeles. They concluded that although formerly, language and health beliefs were considered to be important barriers to access, the current primary barriers are low SES, lack of insurance and organizational barriers. Perhaps this is true in an area like California, where Spanish speaking and Hispanic providers might be encountered more frequently. However, it is not clear what the authors consider “organizational” barriers. They may be cultural factors that are not necessarily conceptualized as “health beliefs,” which are different for providers and patients. In the same way, when Solis et al (1990) conclude from their analysis of the 1982-84 Hispanic Health and Nutrition Examination Survey (HHANES) that having insurance (which they call “access”) is strongly related to utilization and culture is not, they are referring only to the dimensions of culture measured in HHANES and considering utilization of health services as the endpoint of health care access.

While the majority of the problems with access to health care for Latinos in the U.S. may be related to insurance and poverty, there are indications of other cultural factors that may affect use of health services. Schur and Albers (1996), after an extensive bivariate study of access to care using estimates, concluded that financial barriers, including insurance status, are the main problems Latinos face to obtain health care. However, they do mention other factors, such as language and “beliefs,” as important for access. Vega and Amaro (1994) say that if all financial barriers to access were removed, there are still provider characteristics i.e., location, language, and cultural competence), which would pose an obstacle for Latinos accessing the health care system. Authors such as de la Torre et al (1999), Riedel (1998), and Weinick and Krauss (2000) also mention the existence of socio-cultural factors, though they do not define them. The first obstacle to evaluating the role of culture on health care access is that most studies focus on health care utilization as the final result of

access. Most fail to take into account what happens after the encounter. Was the client satisfied? Did he or she follow instructions? Was there continuity of care? The second obstacle is that defining and quantifying cultural factors that influence access to health care is difficult at best. What are these “cultural” factors?

In the quantitative part of this research, we attempted to measure cultural differences by using an acculturation scale. However, as has already been pointed out, that scale measured only the dimensions that were included in it. There might be other cultural aspects that were not well defined, or easily quantified, but that have an influence on realized access to health care. It is a mistake to believe that because we used a measure of “culture” we were able to measure such a complex factor. As Zambrana (1996 a) says,

“The role of cultural attitudes and perceptions has not been directly studied. Rather, most investigators have used acculturation as a measure of cultural attitudes. Acculturation has been measured as a set of variables on language preferences and proficiency and other demographics, such as place of birth, and educational level. However, acculturation measures neither provide us with an understanding of how a cultural group perceives health practice, nor measure health behaviors from a cultural perspective” (p. 76).

She recommends that language and culture be studied as different entities than socioeconomic status, thereby enabling the separation of the individual effect of each set of variables. For the above reasons, it is paramount to explore language and other cultural factors that affect care in a qualitative manner, at least until better quantitative measures can be developed for them.

### 1. Language

In the survey, almost 23% of Latinos indicated that language was a difficulty for them when obtaining health care. Frequently, during informal conversations, Latinos in SWPA mentioned they had problems with health care due to language incompatibility. Additionally, several people had difficulty filling out forms in English, as exemplified by two interviewees who asked me to assist them in filling out health care related paperwork. Language barriers pose

a problem not only for use of health care in SWPA, but also for its effectiveness. In several cases, patients did not understand what was being said to them. For example, a health educator from the United States told me that when she finished a session for a group of low income women in an area near Pittsburgh, she found out that two of them were Latinas. One spoke little English; the other spoke no English. Obviously, they could not make the best use of the educational session. People with fewer years of formal schooling, such as many of the service workers I met during participant observation, seem to experience language problems more frequently than those with more formal schooling. However, some people who probably had many years of education, especially those who were financially dependent on someone else, also had a hard time with language. This was frequently the case for spouses or children of individuals who had come to the U.S. to work or study, but who did not work or study themselves and were relatively isolated.

That quantitative data showed no difference in having had medical services, having had dental services, or being satisfied with care by English proficiency might be due to a combination of factors. One is the small sample size, another is the inadequacy of the measure of language proficiency (as explained in the methodology section), and the last might be the existence of ways to circumvent the formal system. I call these “informal arrangements”, and they will be explained in the next chapter.

In Arizona, Kirkman-Liff and Mondragón (1991), found that Latinos who interviewed in Spanish because they were not able to do so in English had more problems accessing health care than those who were able to interview in English. The authors conclude that language is stronger than ethnicity in predicting those problems. They conclude that language is not a problem per se, but rather it is an indication of diminished education, poverty and lack of access to health care. However, there is evidence that this view is biased. Regardless, in the SWPA sample, foreign-born Latinos of all educational levels chose Spanish as the language of preference for their interview much more frequently than English, even though many of them were highly proficient in English.

The U.S. Department of Health and Human Services (2000) defines individuals with limited English proficiency (LEP) as people who “cannot speak, read, write, or understand the English language at a level that permits them to interact effectively with health care providers and social service agencies.” Jacobson (1999) says that 32 million people in the U.S. speak a language other than English at home; 54% of these speak Spanish. Latinos nationwide report language problems when accessing the health care system (De Santis & Halberstein, 1992; Giachello, 1996 b; Sherraden & Barrera, 1995; Solis et al, 1990). This is not surprising, since 78 to 80% of them are more comfortable speaking Spanish at home, according to Balcazar et al (1999), Chang and Fortier (1998), Jacobson (1999), and Perkins and Vera (1998). Balcazar et al add that 40% of Latinos speak English with limitations. Flores et al (1998) conducted a clinic-based study in Boston and concluded that, after health insurance, language was the single greatest barrier for health care faced by Latino children in low-income clinics. In their study, 15.4% of the patients spoke only Spanish, and they had no interpreters. In another clinic-based study in Chicago, Lipton et al (1996) found that even when most Latinos spoke only Spanish, many received written information that was only in English. DeSantis and Halberstein (1992) have found that patients in Florida had problems with language, including when filing out forms and understanding literature.

*a. Language Compatibility and Translation*

In response to language problems, many Latinos in SWPA tried to find Spanish-speaking providers. Even a provider that spoke little Spanish was preferred over one who spoke no Spanish at all. Sometimes this was not feasible, because patients did not know where to find a Latino provider and were not connected to a network of people who could provide such information. Sometimes their insurance plan failed to include any Spanish-speaking providers. In such cases, they might enlist the help of a relative, a neighbor or a friend as a translator. This was a partial solution, because it is not as effective as if they were able to communicate directly with their doctor. The presence of a third party, even if it was a family member, made understanding the doctor more difficult. Most Latinos think that translators or services in Spanish should

be offered. Even those Hispanics who believe that every person in the U.S. should learn English feel that translation should be available when obtaining health care. Informants said this was especially important in cases where the patients were recent immigrants or too old to learn a new language.

Chang and Fortier (1998) describe two main methods of dealing with language problems in a health care setting. The first is to link LEP individuals with a language compatible provider. The second involves some form of translation. Several authors recommend the use of professional translators for health care visits. To be successful, translation in a medical setting requires knowledge of the provider and patient's world view. It is more than translating words. Brooks (1992), Jacobson (1999), and Pérez-Stable (1987), separately say successful medical translation involves translating complex idiomatic expressions and non-verbal cues, such as moves, looks, and understanding when touching is appropriate. They say that translators who are not fully trained or who are not bicultural might do more harm than good to the medical encounter. Haffner (1992), Jacobson (1999), the Office for Civil Rights (2000), Pérez-Stable (1987), and Riddick (1998) warn against the risks of involving family members, especially children, as translators. Translation of medical terms may be inaccurate, confidentiality might be violated, and their presence may add to discomfort for the patient. Children who act as translators may themselves suffer from psychological problems as a result of the information exchanged during the medical encounter. It was surprising that Haffner, a professional translator working in California, a state with many Latinos, advocates the hiring of more professional translators as the best solution, yet says nothing about training and hiring more Latino health providers. In contrast, Jacobson (1999), the Office of Civil Rights (2000), and Pérez-Stable (1987) believe that hiring more bilingual providers is the best solution, and hiring professional translators is the second best solution. After all, a translator turns the patient-provider relationship into a triangular one, making it more difficult to communicate and build rapport. In SWPA, most people with whom I talked about it, would have preferred to see a Spanish speaking provider than to have a translator, professional or otherwise.

There is a legal framework in support of offering services in a language the client can understand (or, at least, offering translators). Fortier et al (1998) review the history of the legal treatment of language incompatibility in social services in the United States. Chang and Fortier (1998), the Office of Civil Rights (2000), Jacobson (1999) and Perkins and Vera (1998) explain that Title VI of the Civil Rights Acts of 1964 protects clients who access federally-funded programs against national origin discrimination. It prohibits not only intentional discrimination, but also practices that appear neutral but have a discriminatory effect. Woloshin (cited by Hornberger 1998) recommends same language encounters to meet the needs of LEP individuals seeking access to health care. In Woloshin's view, English as a second language programs should be promoted to achieve same language encounters. Hornberger (1998) notes that newcomers are likely to continue arriving, making this policy inadequate. In fact, Woloshin's proposal is an example of an apparently neutral policy that would result in discrimination.

The Office of Civil Rights (2000) cites extensive case law affirming the obligation of recipients of federal assistance to ensure that LEP individuals can meaningfully access federally funded programs. According to Chang and Fortier (1998), currently most programs receive federal funds through Medicare and Medicaid. Often providers do not realize that ineffective communication can result in liability, as pointed out by Jacobson (1999) and Chang and Fortier (1998). According to Chang and Fortier, such risk is large, since miscommunication could easily result in disregarding instructions or following them inaccurately. This could in turn result in malpractice suits. The potential risk of malpractice has prompted four states –California, New York, Maryland and Vermont– to legally require hospitals to provide translators to LEP patients. Riddick (1998) adds that advocacy by ethnic and other community-based groups has accelerated that process. Riddick also says that local health departments have traditionally been the first ones to address the needs of immigrants. As existing policy is applied more consistently, bilingual and multicultural competencies may become, according to Vega and Amaro (1995), highly valued in health professionals.

The type of language assistance a provider is required to offer depends on several variables, such as the size of the population served, the frequency of LEP individuals, the types of programs offered, and the resources of the provider. The Office of Civil Rights (2000), Jacobson (1999), and Riddick (1998) say that the best option is the hiring of bilingual providers, although this is an impractical or impossible solution in many cases. Professional translators are the next recommendation. If they cannot be found, then health care providers should formally arrange translation services with voluntary community interpreters. A formal arrangement ensures in writing that the services are provided by interpreters who undergo some training to understand the program objectives, confidentiality issues and cultural sensitivity. According to Jacobson, a problem with volunteer services is that, they allow hospitals to lose sight of the need to provide volunteers and enable them to forget their responsibility. In Riddick's opinion, community interpreters should be used only as a last resort, because the savings they bring about might be easily overridden by lack of effectiveness.

Some Latino health care providers in SWPA indicated that there is a language bank in Pittsburgh, so that everybody who needs a translator is able to get one. It is staffed by volunteers and serves at least University of Pittsburgh Medical Center's Oakland hospitals and Magee-Women's Hospital. However, Spanish monolingual users of health care said that often no translator was available. Even when they had prearranged to have a translator for a doctor's visit, it was common for the person not to show up. When visits were after hours, such as for an emergency consultation, it was nearly impossible to find a translator. This is not surprising, because it is the primary risk identified by the literature for relying on volunteer translators. A few insurance carriers in SWPA hire translators to assist patients in their visits. These are paid translators and, in most cases, they did show up. However, they were not professional translators, and there were some problems conveying messages from the provider to the patient. Sometimes, a request for a translator, or for a Spanish proficient provider, led to misunderstandings. For example, Lillian told me that her neighbor, Iris, was referred to an obstetrician who was supposed to speak Spanish for prenatal care. In reality, the provider's command of Spanish was

poor, not enough to communicate effectively with the patient. Additionally, after three visits, Iris found out that this provider worked at a clinic out of the hospital, and her services were not covered by Iris' insurance plan. Therefore, Iris had to pay for a service that never took place in Spanish, even though language compatibility was the only reason for using that particular doctor. If Iris had stayed with her original provider, her visits would have been covered.

There was a mismatch in what some Latino providers believed about the availability of translators and what Latino patients experienced. Several Latino health providers thought of language barriers as those faced by patients who came directly from Latin America for care in SWPA, such as those in need of organ transplants. Apparently, those patients were provided with translators for all or most of their contacts with the health system. Many providers fail to see that Spanish monolinguals residing in SWPA have an unsolved problem. Latino providers are misinformed about this issue, and they are disconnected from the monolingual Hispanics in the area. Part of this problem might be explained by the socioeconomic differences and conflicts found among SWPA Latinos. Providers belong to the middle class, and many monolingual Spanish speakers are people with few years of formal schooling and/or low income. A few Latino providers are informed and concerned about language barriers faced by Latinos in the area, but they are not necessarily networked. Latino health providers have failed to organize to mitigate this problem. In this instance, lacking cohesiveness has led the Latino community to miss an opportunity to take action.

*b. Language: beyond translation*

Language also has a cultural dimension and, as Furino and Sumaya (1992) say, "language is the mirror of the culture it defines." Jacobson (1999) says that language cannot be separated from culture. Language affects our worldview, as our worldview affects language. Native Spanish-speaking Latinos in SWPA, several of whom were highly proficient in English, told me in informal conversations that they could tell a Spanish-speaking doctor all of their problems, but that they could not do the same with a non-Spanish speaking one. For them, it was especially difficult to communicate about things as

personal as health care issues in a different language. Regardless of English proficiency, this difficulty appeared to be greater when they felt sick. Thinking in English requires an extra effort that several native Spanish-speaking Latinos found difficult when they were sick. For example, Magaly's mother, who died from cancer, felt relieved when she could talk to a Latin American doctor, even though his care did not affect the prognosis. She told Magaly that she could not express what she felt in English.

Not all words or phrases can be translated and some have no meaning when translated (Stavans, 1995). According to Gutfreund (1990), a shift in language may imply a shift in social roles and attitudes. He studied 80 subjects from a linguistic and psychological point of view. He found that language is one aspect of our early upbringing that impacts us throughout our entire lives. He says,

“learning another language is not simply learning a new task. Learning a new language involves deep feelings that are intrinsically connected to the why and when of learning that language.” (p. 607)

According to Reichman, native Spanish-speakers who are feeling distressed or sick may be more willing to communicate in Spanish than in English. The language spoken at home can bring out positive feelings, such as intimacy and solidarity. Haffner (1992) quotes P.A. Poma, “the language of our childhood remains the language used during times of intimacy and stress” (p. 259) an accurate description of what I found to be the case among Latinos in SWPA. Reichman found that it is easier to express affection in Spanish than in English. Gutfreund (1990) also found that both native English and native Spanish speakers, all of whom were bilinguals, were able to show more affection and were more comfortable expressing their feelings when they were interviewed in Spanish. Regarding affection, Reichman says that Spanish statements are more personalized than English ones. English statements tend to be more distant and, in some sense, more objective. For this reason, Spanish may be the language one chooses, consciously or not, to express somatic or psychological pain.

The Office of Civil Rights (2000) states in its “Policy Guidance” that health services, by their very nature, require the establishment of a close relationship with the client, based on empathy, confidence and mutual trust. The Office further states that such a relationship depends heavily on the flow of communication, which might be difficult if the provider and client speak different languages and that, to a monolingual speaker, language might be an immutable characteristic. Jacobson (1999) affirms that people are generally more comfortable discussing certain topics, such as health and health care, in their native language, and language is the means by which physicians and patients achieve an empathic relationship.

An additional problem is that differences in language may lead to misunderstandings between providers and patients. Reichman (1997) says that questionnaires can be perceived in different ways when administered in different languages. For example, Fabrega (1990) mentions that some Spanish speaking psychiatric patients are found to be more severely ill when interviewed in English than when interviewed in Spanish.

Burciaga Valdez et al (1993) believe that physicians who came to the U.S. in the 60’s and 70’s and were serving Latino communities are now retiring. They say that new native Spanish speaking physicians have not replaced them in sufficient numbers. Holly (1997), advocates for the creation of a health program to serve Latinos in SWPA, stating that a lack of translators is a problem. She also portrays some native English speaking providers as “insensitive.” Perhaps this insensitivity is a lack of cultural competence. Non-Latino providers might misunderstand the way Latino patients view their health problems and the health system. As Reichman (1997) said, being bilingual does not mean being bicultural; being bicultural does not mean being bilingual. She cites Ochs and Schieffelin,

“Becoming sociolinguistically competent – a more sophisticated form of biculturalism than just bilingualism– involves not only mastering a language’s grammatical forms but also internalizing the sociocultural norms associated with that language as well as the indexical relationships between language use and sociocultural context.” (p. 359)

The findings of both this research and the literature reviewed support the idea that language has to do with the meaning of words and the cultural aspects of communication.

*c. Is language a problem of clients?*

The language problems outlined above occurred because many Latinos lacked sufficient command of English to take full advantage of health care visits and most providers lacked sufficient command of Spanish to provide meaningful care to Spanish monolingual patients. Often, providers and policy-makers tend to see language and culture as problems or flaws of the population, even when they advocate cultural fairness and understanding. This view is common in popular media (Kilborn, 1999), but more troublesome, it also appears in periodicals directed to professionals. For example, in an article in the *American Medical News*, Landers (2000) says many immigrants are wrongly denied care, and this situation should be corrected. Landers also says, “Immigrants’ inability to speak English presents a huge obstacle to adequate health care” (p. 7). This statement implicitly blames the patient for their lack of adequate care. This is highlighted by consideration of other ways this fact could have been written. It could read, “Providers inability to speak the immigrant’s language presents a huge obstacle to adequate health care,” or even a neutral, “Language incompatibility between client and provider represents a huge obstacle to adequate health care of immigrants.” Healthy People 2010 mentions that

“Healthy People 2010 is firmly dedicated to the principle that –regardless of age, gender, race, ethnicity, income, education, geographic location, disability, and, sexual orientation– every person in every community across the Nation deserves equal access to comprehensive, culturally competent, community-based care systems that are committed to serving the needs of the individual and promoting community health.” ( DHHS, 2001, p. 9)

It is clear the federal government’s various health agencies are committed to the idea that everybody deserves to receive culturally acceptable services. However, in the same document, HP2010 includes cultural and linguistic

factors in its list of “patient’s barriers to health care,” not in its list of “provider” or “organizational barriers.” It says,

**“Patient barriers:** Any mental, physical, or psychosocial condition that prevents an individual from accessing needed health care. Examples include attitudes or biases, mental disorders or illnesses, behavioral disorders, physical limitations, cultural or linguistic factors, sexual orientation, and financial constraints.” (p. 1-39)

These contradictions arise because often bilingualism is seen as a handicap, rather than as an achievement, as explained by Furino and Sumaya (1992) and Ruiz (1982). This problem affects not only the health care field, but also the education field. According to Silvestrini (1997), bilingual education in the U.S. sees (Spanish) language as a problem. It attempts to “fix” this problem, so that immigrants can become a “normal” part of the nation. This view is not only one-sided, but also discriminatory. It may explain why in a survey of Chicago health providers (cited by Giachello, 1996 b), 50% of the respondents said that Latinos should learn English and not expect that services should be provided in Spanish. Balcazar et al (1999) present the situation from the point of view of patients, when they say, *“la falta de personal médico que hable español es una barrera muy importante en la provisión de servicios e información de salud pública”* (p. 3) (“the lack of Spanish speaking medical personnel is a very important barrier for the provision of public health services and information”.) On the contrary, Jacobson (1999) and Vega and Amaro (1995) see language compatibility as a provider characteristic. Jacobson explicitly rejects the framework of “language as a problem” stating that “languages are **resources** to be managed, preserved, developed,” (emphasis added) and that they serve to enrich our communities. This non-discriminatory point of view is the one that would more objectively reflect the situation.

Many Latinos in SWPA encountered providers who made every effort to understand them. Some providers tried to learn some Spanish words to communicate with their patients; some made signals and gestures. In some offices, several members of the staff participated in this attempt to communicate. Patients greatly appreciated this behavior. Even when it did not really solve all communication problems and understanding details of the

conversation might have remained difficult, patients said they were more eager to follow instructions from a provider who tried to communicate with them. These providers were perceived as being on the side of the patient, as caring for them. Other Latinos encountered providers who made no attempts to communicate with them or who became intolerant when they were not understood. Latino patients felt lost or powerless when they were unable to communicate, especially if they felt nobody tried to communicate with them. Language barriers were not separate from cultural sensitivity and discrimination, and the attitude of the provider, regardless of his/her command of Spanish, could make a difference.

## 2. Views on prevention and urgent care

Apparently, the definition of urgent is not the same for Latino patients and health care providers in the U.S. For providers, a serious health concern should prompt the patient to seek medical care immediately. However, although many Latinos in SWPA believe their health problems are important, they think the problems might just go away over time. They tend to “observe” them at home, possibly using home remedies in the interim. For example, Carmen waited almost a month before seeking care for her pain. She thought the problem could solve itself, and she could not pay for medical care. When the condition worsened, she felt she could not stand the pain any longer, and went to the emergency room. The emergency room providers did not want to see her. They told her that if she had waited a month, it could not be an emergency. Carmen was convinced that they should know that if she came now, after one month, it was obvious that it had become an emergency.

Some felt that home visits were needed for appropriate health care. Octavio said that he had to choose between waiting many days for an outpatient appointment and being rushed to the hospital in an ambulance for hospitalization. He felt there was no middle ground, no real option for health concerns that were urgent, but not life threatening. René, a man in his thirties, went to the emergency room because he felt chest pain. After doctors ruled out a heart problem, he was told that his visit was not covered by his insurance, since it was not a heart problem. René wondered if he should have waited to be

dying of a certain heart attack to go the emergency room, so that the visit would be covered.

The literature says that Latinos lack an orientation toward preventive care. In Rhode Island, Fulton et al (1995) found that low income Latinos were less likely than low income Whites or African Americans to perceive breast cancer as curable and mammography as a safe procedure. St. Germain and Longman (1993) found in Tucson, AZ, that Latinas are likely to see prevention as a strange concept. Many believe that going to the doctor without being ill is asking for problems. Rivera-Tovar (2000) found from her own experiences that prevention is a low concern for Latinos.

Prevention was an important concern of some Latinos I spoke with during participant observation. In informal conversations, several Latino adults in SWPA said they never miss their checkups and attend all their appointments punctually. Some, however, said they never went to the doctor, unless they were very sick. Prevention was not a main concern for many of them. For example, some service workers worked 11 hours a day six days a week and worried about being able to feed and clothe their children. Another main concern for many of the service workers was to be able to send some money to their family in their country of origin. As for any other low-income group, prevention for Latinos has to be put in the context of daily life. According to Moreno et al (1997), prevention is understandably a secondary concern when there are other, urgent problems to deal with on a daily basis, especially for low-income families. In those cases, locus of control may be an issue, too, as pointed by Schensul (e-mail of February 12, 2000). This is reportedly common among most low-income groups (Friedl 1978). After all, a person who works many hours for low pay has little **real** control over his/her health care.

While low prevention orientation might be more common among people with fewer years of formal schooling, some middle class professionals in SWPA also believed they did not need to use preventive services. They believed themselves to be healthy and thought preventive care would be a waste of time and money. In some cases, even people with insurance did not use preventive services covered by their health plans. They frequently postponed visits because they had no time or believed the care was not important. Some women regarded

Pap smears and mammograms as being nuisances. For example, Amalia had gotten only two Pap smears in thirty years in the U.S.; she got the last one only to please her children.

In informal conversations, many said they keep all their dental appointments. However, many more said they do not, and some said they are proud of not having gone to a dentist in years, feeling it to be an indication they had “good teeth.” Many go to the dentist only when they have a toothache. Dentists are considered especially expensive, and dental preventive care visits are commonly regarded as unnecessary. Dental care is low on the list of priorities of SWPA Latinos. The literature presents inconclusive evidence regarding dental care. Apparently, the perception of low importance of dental prevention coupled with low ability to pay for dental care results in underutilization of these services. Davidson et al (1996) found that Latinos have fewer contacts with dental service providers than Anglos, but that they were similarly concerned. They attributed most of the difference to having insurance and having a regular source of dental care. Other studies among Latinos found that those with low acculturation have more decayed and missing teeth than those with high acculturation, and use dental services less often. This would explain why we found no difference by income or English proficiency, but there was an almost statistically significant difference by acculturation in the proportion of Latinos who saw a dentist in the past year. In the Southwest, Ismaili and Szpunar (1990) report that 25% of low acculturated Latinos had never sought dental care compared to just 6.1% of highly acculturated Latinos. They attribute most of the difference to socioeconomic status. Lower income Latinos tend to go to the dentist only for extractions or because of a toothache, but seldom for preventive or restorative services. Our research does not agree with this data; income was found to be unrelated to use of dental care. Aday et al (1998) say that enabling factors, such as health insurance and a regular source of care, are more important than need in determining utilization of preventive services and dental care.

Some Hispanics in SWPA had not been socialized to believe preventive care was important. They said their parents did not take them for medical or dental checkups. Some even said their parents were proud of rarely having seen

a doctor, regarding this as to be proof of good health. A couple of people told me they were proud of rarely or never going to the doctor, for the same reason. Some, however, appreciated preventive care. In informal conversations, they said it is necessary to educate children about the need to use preventive care, so that they continue to do so when they grow up. They also said that learning to use preventive care would be easier for their children than it had been for them, since the emphasis on prevention was higher in the U.S. than in their countries of origin. Consistent with this, among the people encountered during participant observation, those who were raised or had been here for a long time seemed to be more concerned about preventive care than recent immigrants. Additionally, this data support the notion that some cultural views –and not only socioeconomic status– determine prevention orientation of Latinos in SWPA. However, more study is needed around this issue.

Those Latinos in SWPA with heightened awareness of a particular health problem, reported being concerned about obtaining preventive health care, such as checkups or screening. For example, individuals with family histories of cancer or hypertension reported that it was very important for them to get periodic checkups because they feared developing those conditions. Others reported going to regular checkups because of previous health problems they now believed could have been prevented through early detection. In these cases, people made an extra effort to get care, sometimes even when they did not have insurance coverage. This sounds quite logical and has been reported elsewhere (St. Germain and Longman 1993).

Even though prevention in general was not high on Latinos' priority list, utilization could be increased if existing barriers, such as lack of coverage, discrimination and language incompatibility, were decreased. For example, Antonio said that he actually liked to get his checkups. When he lived in Virginia, he had checkups every six months at a free clinic with Spanish speaking providers that were nice to him. Here, in SWPA, he did not go for checkups, because he had no insurance and could not find a place similar to the one he attended in Virginia. In this case, availability of affordable and culturally appropriate services determined the use of preventive care.

### 3. Relationship with providers

#### *a. Ethnicity*

Many Latinos in SWPA said they preferred Latino doctors. Some, however, said they were indifferent to the ethnicity of their doctors, as long as they were good professionals. Interestingly, several of the individuals who claimed to be indifferent about their provider's ethnicity actually saw Latino doctors.

Some Hispanics with fewer years of formal schooling were really upset and resentful about the lack of cultural compatibility between themselves and U.S. doctors. They also resented being treated like children and required "distance respect." In contrast, two Latinos said they preferred Anglo providers. One of them, a retired professional, felt that the Latino community in SWPA is too small and feared a lack of confidentiality. Her provider could discuss her case with other people, she could be easily identifiable, and her privacy would be invaded. The other, a Mexican service worker, said that he preferred anything but Mexican doctors, who always treated him as "lower class." However, most low-income Mexican people I talked with had tried to find Latino doctors, Mexican or not. A couple of people said they preferred a foreign doctor, regardless of his or her ethnic origin. They said they were able to establish a better connection with other immigrants than with U.S. doctors, and they expected immigrant doctors to have more desirable bedside manners.

These findings are neither new nor surprising. In a historical article about immigrants' attitudes towards doctors in the U.S., Kraut (1990) presents some interesting accounts of European immigrants early in the twentieth century. For example, Italian immigrants preferred to call Italian doctors, due to language compatibility. However, often immigrants preferred immigrant doctors, regardless of what ethnic group because they stayed longer with them, developed personal relationships and explained things better to patients and family. Kraut says, "Immigrant patients often assessed physicians by the warmth of their manner and the bitterness of their medicine" (p. 1089).

*b. Personal relationships*

Latinos in SWPA appreciate relationships with their providers that are personal and warm. They want their providers to treat patients as special people, take time to explain things, and consider options. Often, such encounters include some physical contact, like touching hands or the provider touching the shoulder of the patient. Usually, it took Latinos some time to find providers who fulfilled the above description; some never did. Preferences regarding provider characteristics were similar to those listed by Pérez-Stable (1987). He says that respect is expected in a form of formal friendliness, as well as some physical contact; physicians might be evaluated mostly on their people skills. Ruiz (1995) says that Latinos often use non-verbal ways of communication, and Sherraden and Barrera (1995) found that Mexican immigrants in Chicago appreciated a personal connection a committed provider. According to Rivera-Tovar (2000), Latinos value information that is based on personal experience or an acquaintance's experience more than percentages and scientific facts. This is all in tune with the cultural concepts of *personalismo* and *simpatía*, the way Hispanics are supposed to value time, and their preference for smaller personal spaces (Marin and VanOss Marin 1991).

One common complaint about doctors and other health care providers in the U.S. is that they are cold, distant, impersonal or business-like. Some said their doctors saw them at such a fast pace that they were confused. People said that doctors always appeared to be eager to leave the room. For example, one man said that his doctor, after examining him, would take hold of the door handle, partially open the door, and ask, "Is there any other question?" He wondered why the doctor even bothered to ask, since it was obvious he just wanted to leave. Even though, in general, U.S. doctors are considered to be polite, they are also perceived to be distant. Several people said there was no eye contact, which was interpreted as a lack of sincerity or concern for the patient. "They never touch you," a man said. He added that his doctor made him feel as if he had a contagious disease. "They look at you with binoculars," from afar, another individual said. A patient might wait for an hour, then be dismissed in five minutes, with the doctor never having looked at his face. These complaints were not only heard about physicians and conventional

medical staff, but occasionally also about homeopathic doctors and other less traditional providers.

Some said that U.S. doctors did not talk to them; they just gave them a pill. They believed this happened because U.S. patients wanted just that, a pill, to get cured.

Affluent Latinos cited these problems perhaps more often than lower income Latinos did. Affluent or more educated Latinos, however, did not stop seeking care because of this. They believed that U.S. providers could not change the way they were. Edmundo thought his doctor did what he could, and he appreciated his efforts. However, he could never be friendly, like a Latino, Edmundo added. Tito, who was very wealthy and had attended graduate school, said his doctor was very good, but could not help being like he was, because he was from the U.S. When I asked for clarification, he said that he always got the best treatment and never had to wait, but he missed his doctor in Mexico, because he *“era muy cuate”* (“was like a friend”). Others rationalized this lack of personal treatment by blaming it on the system. Now that insurance plans are the rule in health care, the way professionals worked had changed and physicians have less control over their time and the way they worked. All these complaints are consistent with the preferred characteristics of providers expressed by the same population.

A recurrent theme among Latinos in SWPA was the belief that Anglo providers would treat patients as “specimens” or *mercadería* (“merchandise”), not as human beings. *“Yo soy un ser humano y quiero ser tratado como tal”* (“I am a human being and want to be treated as such”). People explicitly said that they were treated better in Latin America, when they went to the doctor. However, it is likely that they either spoke of an “idealized version” of Latin American doctors, or that their experiences were mainly with the private system in Latin America. In one case, however, a man cited excellent experiences with the public health care system in his country of origin. Another said that in his country’s public hospitals providers were warm, even though material conditions were really inappropriate.

Not all Latinos complained about the treatment from U.S. doctors. Several individuals actually praised the personal and human characteristics of

their U.S. physicians. They said their doctors were receptive, polite, took their time to listen to them, and took a personal interest in their cases. One woman said she had been treated “with the special consideration you give somebody who is going through this thing.” A Latino physician, during an informal conversation, recommended a specialist for my husband. He regarded him highly, and said he was very satisfied with his care. Lastly, to convince me, he added that “*no es el típico médico gringo...te mira a los ojos*” (“he is not the typical U.S. doctor... he looks you in the eye”). This type of praise only stresses the characteristics that Latinos expect from their providers. Apparently, it is not important what ethnicity the doctor is; it is important how personal and caring his/her behavior is perceived to be.

In general, patients praised the technological advances of medicine in this country, which they believed could not be found anywhere else in the world. They said that if you could pay for it or if you had insurance, you could get it. Many believed that within the U.S. system, they had been treated well. However, if they had to choose, some would prefer personal, warm treatment to a high tech, cold approach. Octavio said, “*En los hospitales públicos en América Latina uno se muere porque no hay nada, pero se muere contento. Aquí uno dura, porque hay todo, pero dura amargado*” (“In Latin American public hospitals, one dies, because there is nothing. But one dies happy. Here, one lasts (lives longer), because there is everything, but one lasts embittered”).

In SWPA, as in the literature, Latinos and immigrants appear to expect a personal relationship with their providers. They might misinterpret a less personal relationship for insensitivity and indifference, as explained by De Santis and Halberstein (1992). This could be really the case for everybody, not just Latinos, as Schensul pointed out in a personal communication (e-mail of February 12, 2000), “We all prefer a personal relationship, but don’t get it anymore.”

### *c. Conveying information to clients and patients*

A few Latinos told me stories in which bad news was given to them in a totally impersonal and uncaring way. They felt providers were not sensitive to their concerns and situation. Eloísa said she was told in the waiting room,

without any introduction, that her tumor could be malignant. She was overwhelmed by the news, and at the same time, she felt her doctor did not support or understand her. She said she would have expected a more private setting and a more caring way of telling her about her diagnostic possibilities. Separately, two people recounted visits to the emergency room following accidents, when nobody would give them pain medication, or an explanation about why they could not receive it. Alfonso told me that when his wife had a massive heart attack and was in agony, the doctors took him, almost by force, out of the room. They told him he had to leave because she was dying. He was, after many years, still furious, because those doctors did not understand that he wanted to be with her precisely because she was dying.

Several Latinos have preconceived ideas about U.S. health care providers. One might think this could be explained because Latinos have no contact with U.S. health providers. Sometimes, however, having contact with them has reinforced these preconceived ideas, as in the example of the Alvarado family. The Alvarados were convinced that U.S. providers were not caring enough and never explained things clearly. They had health insurance in their country of origin because they never wanted to see a provider in the U.S. However, one day, their little girl played with snow, then took a hot bath. The next day she woke up with pain in her leg; she could not walk. They went to the emergency room, where she was examined. Several doctors came in several times during their visit, which lasted from early in the morning until 9 p.m.; the girl was not allowed to eat during this time. Doctors looked more and more worried each time, but told the Alvarados nothing for a few hours. They took X-Rays, then told the parents that the child might have a serious disease, involving her immune system. They needed to do blood work. The parents spent several hours agonizing over the possibilities. Only at 9 p.m. were they told that the pain was nothing, perhaps a muscle contraction due to the difference in temperatures of the snow and the subsequent hot bath. They could leave, and no prescription was necessary. When I met the child, one year after that episode, she was pretty healthy. The Alvarados thought that their grandmother could have told them faster that the culprit was the cold. After this experience,

they were even more convinced they should never again go to a doctor in the U.S.

*d. Information, trust, detachment and paternalism*

A common opinion among Latinos was that they did not receive enough information about treatment or diagnosis. In some cases, this led to misunderstandings that made treatment more difficult. Clara, a Spanish monolingual woman, was hospitalized and supposed to fast for an exam. The chart said “N.P.O.,” but Clara did not know what that meant and had not been told she had to fast. She thought the food service was slow and that was why she did not get her breakfast early. Her daughter gave her something to eat. As a result, her exam had to be postponed. Clara interpreted this miscommunication in a cultural way as lack of caring.

Some Latinos in SWPA complained of bad quality of care and said they did not trust their providers. For the most part, these opinions were caused by a combination of a bad experience with the health system and bedside manners that were different than expected. In an extreme case, Ramona used to take a hidden tape recorder to her medical visits. In case of malpractice, she wanted to have proof of what was said. Lack of trust, justified or not, can lead to lack of compliance. This not only wastes resources, but also might further jeopardize the patient’s health status. Several people had not had a bad experience with the system, but still distrusted U.S. doctors and dentists. It was not clear what triggered this distrust, but it led to ineffective care, as instructions were often not followed.

Some believe Latin American providers have a more global vision of the individual and take an interest in the whole person. Here, they believe doctors divide the person into little parts. Each specialist sees only a part of the person, then prescribes pills for that part. Etelvina said about her experience here that

*“no siento confianza en el médico, es como un double guessing todo el tiempo. Me parecen inexpertos, no te tratan como persona. Si fueran Latinos serían more caring y warmer. They would show more concern. Perhaps these are my stereotypes...Yo me siento débil y espero que tengan experiencia, cuidado, preocupación. Si me lo soluciona o no, no me interesa, por*

*último...Te da vergüenza demostrar que tienes dolor, eso es aquí, no sé por qué* (“I don’t feel I trust the doctor, it is like double guessing all the time. They seem inexpert, they don’t treat you like a person. If they were Latinos, they would be more caring and warmer. They would show more concern. Perhaps these are my stereotypes ...I feel weak, and I expect them to have experience, care, concern. If they solve my problem or not, ultimately doesn’t matter...You feel ashamed to show you feel pain, that is here, I don’t know why”).

Quite a few people said that doctors in the U.S. refuse to give final diagnoses and/or recommendations for one treatment over the others. Some believe U.S. doctors do not commit themselves; they just want to “wash their hands” and take no responsibility. They feel doctors here are defensive, fearing a lawsuit, and do not recommend what they believe is best in terms of exams or treatment, because of this fear. Others believe it is not fear, but detachment when they make the patient choose. While Americans might see this as giving more options to patients, some Latino patients felt abandoned with difficult decisions they were not prepared to make on their own. It was common for Latino patients to indicate a preference for a more paternalistic relationship with their doctors. They wanted to be told what to do, or at least what was best to do. They needed to feel “protected,” “cared for.” This feeling was shared by people with widely different educational backgrounds, some with many years of formal schooling. For example, José, who had a graduate degree, had a sore throat and high fever. His doctor told him he could have just a virus, but then proceeded to explain to him many diagnostic possibilities, among them tuberculosis and other serious diseases. José was shocked. When the doctor asked him what he wanted to do and what medication he would prefer, he was even more shocked. At that moment, especially being febrile, he needed care and to feel better. It took him days to process all the information, and he felt worse after the visit than before it. With some guilt he told me that he believed Latinos “*somos muy paternalistas*” (“are too paternalistic”). He thought it would have been better for him to make his own decisions. However, he was feeling so bad that he was in no position to make those decisions. After a few days, José was healthy again, but he changed doctors, in spite of what he expressed about paternalism. The literature offers some indications of Hispanics’ preference for

paternalistic relationships with providers (Quesada 1976), but the issue is not completely clear. Blackhall et al (1995) say that Latino families try to spare the patient suffering, especially when he or she is old or very ill; Haffner (1992) says that, in her experience as a translator, she observed that Hispanics expect their doctor to make decisions for them. Caralis et al (1993) studied end-of-life decision-making with a group of patients including non-Hispanic Whites, African Americans and Latinos that were mostly Cubans. They found that Hispanics were, regardless of socioeconomic status, more likely to allow their physician to decide on their treatment. However, in the study by Caralis et al, Hispanics did not show a preference for sparing the patient “bad news”; they favored telling the truth to both the patient and the family.

#### 4. Communalism

Latinos in SWPA are more responsive to the health needs of their children than to their own. Most people took getting preventive care seriously when the person in need of such care was a child. They said they keep all their children’s appointments; in fact, most of the children in the survey had a medical visit in the past year. However, when parents are sick and need health care, they tend to wait. A nurse told me that she has seen several low-income Latino parents ask their children’s pediatrician what to do about their own ailments. The nurse believed that the parents needed to see an internal medicine doctor, but they did not have insurance and/or could not afford to pay for care directly; perhaps they had no time to go to the doctor. The nurse also said that many believed that they were healthy and, therefore, they did not need any medical care. They only went to the doctor if they felt extremely sick.

Putting the needs of someone else ahead of one’s own needs has been called communalism, and is one of the characteristics of Latinos Marin (1989) describes. This might be part of why Latinos are more likely to take care of their children than themselves. Latinos expect the same behavior from their doctors and resent it when they find this is not the case. Several Latinos believe U.S. doctors order too many exams and do too much analysis, perhaps because they want to avoid a lawsuit. Sometimes informants feel U.S. doctors give patients an unnecessary treatment just to cover their backs. This is what Estrella’s

parents thought. Estrella was a newborn baby hospitalized because she had a one-time measurement of fever. Otherwise, the baby was all right, and the fever never returned. Cultures and exams were taken; she was given an intravenous line and antibiotics. The results of the exams were all negative and were known that same day. However, the doctors did not discharge Estrella for three days, because they were following their protocol. Her parents felt the response of healthcare providers was exaggerated. They wondered what the real motives were for keeping Estrella in the hospital.

Several Latinos in SWPA believed U.S. doctors, especially dentists, are in their profession for the money and no other reason. One retired doctor spoke about his idea about the practice of medicine, saying he believes in “*ejerger la medicina por el gusto de ejergerla, por el amor al individuo, no al status ni al posible beneficio económico y material*” (“practice medicine or the sake of practicing it, for love to the individual, not for the status or for the possible economic and material benefits”). He feels this is not what happens today, especially in the United States.

#### ***E. Factors that affect utilization of health services: immigration status***

In general, the 1996 Welfare Reform Law prohibits most legal immigrants who have not yet become U.S. citizens from receiving food stamps and social security income. According to Thamer et al (1997), the same law allows an “option to deny” that opened the way for states to deny immigrants other benefits, such as Medicaid. This has resulted in a large portion of poor immigrants being left uninsured.

An additional problem related to immigration, as reported elsewhere by researchers such as Chavez et al (1992) and by the media (Kilborn, 1999) is that Latinos might fear INS tracking, even when they are legally here. Some immigrants erroneously believe they might lose their status if they use free care or other free services, or that they may upset their employers if they use their insurance. According to Brown et al (1999), some Latinos might dislike the idea of getting care in clinics that are for “charity,” hence perceived as being of lower quality and intended for people who are of low status. However, I have found no

direct indication of the latter. Many people I spoke with said that “others” might think Medical Assistance carried stigma or was low quality. When talking about themselves, the uninsured were eager to get any health care, and they welcomed the idea that it could be free. One person said that Latinos might dislike services designed for African Americans. This seems to be an isolated opinion, and when I asked why he thought that, he gave no details, except that he thought Latinos and African Americans were different.

#### ***F. Factors that affect utilization of health services: discrimination***

Some SWPA Latinos believe they were discriminated against and treated as second-class citizens by their health care providers, because they did not speak English or had an accent. Latinos who look white feel that they were treated differently once the provider heard their accent. Some believe that if they erased their accent, they would not be discriminated against at all. Others feel that providers discriminate against patients when they “look” Latino, meaning brown-skinned.

Discrimination could take several forms. One way, easily detected, happens when a provider purposely insults a patient. Some people said a provider had yelled at them, made fun of their looks, or ridiculed their beliefs. For example Jesusa, a U.S.-born, dark-skinned woman, said that a non-administrative employee of a hospital asked her for her green card. When Jesusa stated she was a U.S. citizen, the employee laughed at her and said that he was sure that, “with that face,” she could not be a U.S. citizen. Most forms of discrimination reported were subtler. Sometimes providers act as if they do not understand the words of the Latino patient, even when they do understand. The fact that this could not be proven is a source of frustration for some Latinos in SWPA. However, it is an extremely common complaint and one I remember experiencing myself.

Another form of discrimination, sometimes well intended and perhaps more frequent, involved patronizing. Some health care personnel would speak as if the Latino person was unable to understand or follow instructions and in need of extra explanations. Latinos also said that Anglos often spoke more

loudly to them, believing that in some way they would understand English better if it was spoken louder. Yet, another form of discrimination was the provider not giving enough information about the patient's condition, because he or she considered the patient unable to understand a complicated explanation. Mostly, these complaints were about receptionists and non-medical staff, but some also cited discrimination by doctors.

Some patients feel they are not taken seriously because of their ethnicity. Their providers try to minimize their concerns as unimportant and/or exaggerated, and tend not to believe the patients, even when faced with evidence supporting their claims. For example, a Latino physician, Dr. Torres, told me his experience. He had just returned from an area where dengue was endemic, and his symptoms included high fever, sweating, and chills. He went to the emergency room and suggested to the staff that he might have dengue. The staff disregarded his suggestions and considered instead a hypertensive crisis, a thyroid disorder and a psychiatric problem as the diagnostic possibilities. Dr. Torres became angry, and the staff wanted to refer him to the psychiatrist for being "agitated". It turned out he had dengue. A related example is that of Flor, who expelled an intestinal worm. She told her doctor that she had a parasite and needed treatment. The doctors said that what ailed her could not be a parasite. She took the worm in a glass jar to her doctor's office, but they still would not believe her. They told her she had put a worm in the jar and made up the story. The stool test was negative; they performed a series of X-Rays and an endoscopic exam. Flor was told she had nothing, but she insisted on her story. Finally, she was referred to a specialist, who, after seeing the worm and listening to the story, recommended appropriate treatment. Luckily for Flor, she was assertive enough to insist on her version and demand proper care.

Commonly, Latinos feel that they are not given the "complete" service, that they are taken care of faster than Anglos, and that nobody listens to their concerns. Some feel they had received medical treatments that are not as good or as "state of the art" as the treatment given to Anglos, because of their ethnicity. Olivia said she was not offered the most modern treatment for her ovarian cysts because she had an accent. She reviewed the recommendations

for cases like hers and asked why she was not given the treatment she considered best. She never got an explanation. If it had been the best treatment, Olivia said, they should have explained to her why. Luz felt that she needed a particular type of exam due to her symptoms; she had a friend that was given the exam to rule out the same condition. She felt the doctors treated her differently because she was Latina. Like Olivia, Luz said she never obtained a satisfactory explanation. At some clinics, patients reported not being thoroughly examined. For example, two women said that when they had a complaint, any complaint, they were given Ibuprofen. These feelings are only the “impressions” of patients, and their assertions could not be proven. However, in a study about medical decision-making, Schulman et al (1999) found that doctors recommend invasive cardiovascular procedures less frequently to African Americans than Whites, controlling for age, sex and symptoms. Moore et al (1994) found that among AIDS patients eligible for drug therapy or prophylaxis, 48% of African Americans receive the drugs, compared to 63% of Whites; the difference was statistically significant. Not enough Latinos were enrolled in the study to perform statistical tests. In Cook County, Illinois, McDermott et al (1996) found that both African American and Latino asthmatic patients, are more likely than Whites to receive deficient care when compared to guidelines. Fulton et al (1995) and Polednak (1996) mention that doctors fail to recommend use of preventive services to low income Latinas. Napoles-Springer et al (1996) found that older Latinas do not have Pap smears or mammography performed, even when they see a doctor four times a year. Therefore, the concerns of SWPA Latinos, even if unproven, should not be dismissed lightly.

Giachello (1996 b) believes that many Latinos experience discrimination for the first time when they come to the U.S., and de la Torre et al (1999) says that those who are less proficient in English experience more discrimination. Many Latinos in SWPA, mostly immigrants, did not call the above-described behaviors “discrimination.” I have included them here because subjects did believe they were treated differently due to their ethnicity, race, language, or accent. They only stopped short of calling it “discrimination.” It was more frequent for Latinos who were born and/or raised in the U.S. to say they had experienced discrimination and to complain about it by name. People living in

the U.S. for a long time might have been exposed more to discrimination, were used to hearing people talking about it in this context and responded to it easily. In Latin America, people are not as used to airing discrimination problems as they are in the U.S. The above-mentioned explanations have been advanced by Gonzalez (2000), Keefe (1992) and Trueba (1999). According to Gonzalez (2000), Latinos who have spent a long time in the U.S. might feel more identified as being “Latinos,” they might have developed a “cultural commitment” that makes them respond strongly to discrimination. A few Latinos who had lived in other areas of the country told me that there is more discrimination here than on the West or East coasts, and even more than in places such as Chicago. Perhaps this is due to the higher proportion of Latinos in the population of those areas. U.S. providers there may be more used to dealing with Latinos and might be more sensitive to Hispanic culture. Additionally, it might have been more likely that some providers were Latinos themselves. Underrepresentation in the health professions is part of the problem, as Riedel points out (1998), and this problem is more acute in areas with fewer Latinos, such as SWPA. Health system administrators feel understandably less compelled to recruit minority providers for a small population.

It is more frequent for people with more years of formal schooling to find some “problems” or discrimination with the service they received. Perhaps this is due partly to the difficulty poorer Latinos experience in obtaining health care in the U.S. Perhaps this difficulty leads them to welcome any care. Additionally, foreign-born Latinos with fewer years of formal schooling are more likely to have used the public system in Latin America, which in some cases is a bad one. For example, a middle-class Mexican immigrant said that Mexican doctors in public clinics were just as cold as U.S. doctors and some that were even rude. The waiting time in Mexican clinics was terrible, as was personal treatment. Therefore, the point of comparison was lower than the one of those that had used the private system in Latin America. This same explanation has been given in contexts other than health by Gonzalez (2000), Trueba (1999), and Zsembik and Beeghley (1996).

One way in which Latinos respond to discrimination is by being more assertive. After some experience in the U.S., they said they concluded that being polite and asking favors would be interpreted as being vulnerable, or even subservient. Care had to be demanded for better results. As Freidenberg (cited by Friedl, 1973) said, they felt that “American society is not designed to respond to needs, which are what losers have. Instead, it responds to demands, which are what winners are in a position to make”. Other SWPA Latinos felt bad after facing discrimination during their doctor’s visits. They avoided using health care in the future unless they were very sick, possibly facing a more costly treatment as a result of the delay, both in economic and health terms. As Williams (1994) says, the expectation of ethnic discrimination precluded several Latinos from getting care.

### **G. Summary**

In the past year, 20.9% of Latinos in SWPA had no blood pressure determination, 20.2% had no visit to the doctor, and 33.0% had no visit to the dentist. The proportion of Latinos here who did not visit a doctor was similar to that of Latinos who did not visit a doctor across the nation. Not enough national data are available on visits to the dentist or blood pressure measurements to establish a comparison.

Realized access to care is influenced more by cultural factors than potential access, while financial factors appear to play a lesser role. Income has no significant influence determining utilization of services. Those with low acculturation are less likely to have had a blood pressure measurement in the past year compared to those with high acculturation (31.1% and 9.7%, respectively). Having a source of care and being female are the only significant determinants of visiting a doctor in the past year. These people are seven and six times more likely to have had a doctor visit, respectively. Having a regular source of health care has a borderline influence over having a visit to the dentist. The influence might be exercised through a recommendation to seek dental care by the regular source of care. A larger sample might have helped in finding a significant result.

Approximately one-fifth of the people surveyed were not completely satisfied with their last medical care visit. This was the only outcome affected by a socioeconomic variable in the multivariate analysis: those with education of at least some college were significantly more likely to be “moderately” or “not at all” satisfied with the care they received. People with more years of formal schooling, because of both their higher standard of comparison and their ability to articulate their concerns more clearly were not completely satisfied with care more often than those with few years of formal schooling. Among barriers to health care access mentioned in the survey, the most frequent responses were waiting times, high expenses, and language and cultural incompatibilities.

Even though acculturation has not been a significant predictor of any of the outcomes, the qualitative data reveals the importance of culture in realized health care. Language affects effectiveness of health services, satisfaction, and its later use. For most Spanish monolingual patients, translators are not generally available. Misinformation and socioeconomic divisions among Latinos in SWPA has led several health professionals to believe translators are available. Enforcing the Civil Rights Act of 1964, which requires staff translators or a formal arrangement with trained community translators could solve this problem. However, difficulty stems from the general perception that language is a problem of patients, as is their inability to speak English. The appropriate way of looking at the problem would be to view it as language incompatibility.

Aside from the obvious translation issue, language also means a certain way of expressing things that cannot be easily translated. Native Spanish speakers, even when proficient in English, feel more at ease expressing themselves in their native language, especially when sick. This is consistent with literature showing that an individual needs to talk in her or his native tongue, especially at times of intimacy or stress.

The literature mentions that Latinos’ low prevention orientation influences their use of health services. However, this was not studied thoroughly, and it appears that there are people at both ends of the spectrum. Many Latinos seem to be very careful about obtaining their preventive care, while others consider getting health care when not sick to be nonsensical.

One of the most common cultural factors found to be relevant to realized health care access was a preference for providers who related to their patients in a personal and warm way and who were perceived as being committed. Latinos thought that providers should take their time, look at patients and have certain physical contact with them, such as touching their shoulders. Providers of any ethnicity were praised or criticized according to this ideal behavior. Those who did not conform to it were perceived as being detached. Several patients preferred to discontinue their care under such circumstances. These preferences are in concordance with the concept of *personalismo* advanced in the literature as a trait of Latinos.

Latinos in general feel that many health care providers do not convey information in an appropriate way. They want to be treated as “human beings,” meaning that they want their feelings and opinions to be taken into account during informational exchanges. Paternalism was not explicitly explored during this study, but subjects did say that they wanted their doctors to offer them options and, at least, inform them of their opinion of the best option. Paternalism appeared to be related to the highly valued concept of communalism, that is, putting the interests of others ahead of personal interests. Providers who were perceived as taking actions just to avoid liability, for the advancement of their scientific knowledge or for financial gain, were regarded as acting inappropriately; they should think of their patients first and help them.

The effect of immigration status on realized access to care was not explored here, and it warrants further research. Discrimination exists, although some refuse to call it by name. Its manifestations vary from patronizing, to blatant mistreatment, and not taking the patient seriously to providing lower quality services because of the patient’s ethnicity.

## **VIII. Strategies to overcome barriers to health care access**

### ***A. Introduction***

As seen in previous chapters, often Latinos in southwestern Pennsylvania (SWPA) who need health care meet with economic and cultural problems. Many are uninsured and/or do not have the money to pay for care on a fee-for-service basis. Many find the health care system difficult to understand, because of the language and the bureaucracy involved. Many feel the system is not responding to their needs, from a cultural point of view. What do Latinos in SWPA do to find care when confronted with these obstacles? This chapter will address the resources Latinos in SWPA use to make the best use of the health care system, including community networks and alternative arrangements for care. Finally, I will review some possible solutions for the health care access problems for Latinos in SWPA.

### ***B. Networks as resources of the community***

When Latinos in southwestern Pennsylvania (SWPA) cannot access the health care system, either because they do not have insurance and/or cannot pay for care on a fee-for-service basis, they try to find a different way to satisfy their needs. Browner and Lewin (1982, cited by Chavira-Prado, 1992) said that adaptation is a “set of specific behaviors people devise to attain and use resources and to solve the immediate problems confronting them” (p. 54). This is exactly what SWPA Latinos do. They find out how to arrange their care either through word of mouth or from formal agencies. They use their networks – friends, relatives, fictive kin, church groups, and other organizations– to

exchange favors and information. They help each other with child care and getting to doctors. Many Latinos use these networks to obtain referrals, recommendations and opinions. They talk to one or more acquaintances before obtaining care for an illness through a formal or informal arrangement.

The literature mentions that Latinos often build networks of people to help solve their problems. Keefe (1980) found that in each of three California communities, there is a contact network that exchanges information, a smaller network that exchanges goods and services, and an even smaller network that exchanges emotional support, too. These networks are based on enduring social relationships, but not necessarily on spatial proximity. According to Bassford (1995), Latinos make health decisions within the social network. Referrals or recommendations for care that come from that network are more effective than referrals from doctors. Communities themselves regard social networks as a resource. Ludwig-Beymer et al (1996) found that for members of Chicago Latino neighborhood, the main strength of their community was having access to friends and families to socialize with and to get support from when needed. Wallace et al (1995) analyzed data from two national studies on aging and found that elderly Latinos living with their children receive a great deal of direct care from their children. Those elderly Latinos who live separately, have their children act as brokers between the elderly and the formal system. In SWPA, networks are also a resource; like the ones described by Keefe, they are not based on spatial proximity.

Chavira-Prado (1992) found in her research of Mexican origin migrant workers in Illinois, that women do all the connecting to obtain resources for day to day problems, including health care, and that this stems from their role as mothers. Women are the ones in charge, not only of administering health cures and first aid, but also making health decisions and giving health advice. Freidenberg and Hammer (1998) studied elderly Latinos in East Harlem, a very different group of Latinos than the one studied by Chavira-Prado. They found that social contacts predict addressing medical needs and utilizing the health care system on a regular basis. However, network size and structure were not related with health status and income; physical activity constraints were not related to network size or health care use. In this case, too, women who lived in

the New York area were the ones who made most of the network connections. In SWPA, no attempt was made to investigate whether men or women did most of the communicating. It did not appear to be a pattern of women or men being the main “connectors,” but since data were not collected, this remains unknown. An interesting point of further research would be finding out the role of women in SWPA in the development and maintenance of ethnic networks, Latino or other.

Not all Latinos in SWPA use ethnic networks to get care; some are distanced from other Latinos, either by choice or because they are isolated. Isolation and lack of a cohesive community are barriers to finding better and more varied arrangements for care. Isolation makes it more difficult to establish networks. Word of mouth stops when it reaches the extent of the network. The scarcity of Latino organizations and meeting spaces make it difficult for Latinos to connect with other Latinos in SWPA. Additionally, there are almost no formal services for Hispanics in this area. For the ones who want to advertise their services, it is difficult to reach the community, other than through a few groups that do not cover the bulk of the population.

### ***C. Formal arrangements***

#### **1. Types of formal arrangements**

Formal arrangements for Latinos in SWPA included getting free or subsidized health care without a public or private insurance plan, or going to a neighborhood or other clinic. Many people received health care at local hospitals for free. Several did so through what they called the “Hill-Burton Clinic,” at Mercy Hospital. There actually is no “Hill-Burton Clinic,” but many Latinos gave this name to a mode of free care. In 1946, Senators Hill and Burton introduced a bill in Congress, which when it passed, it became known as the Hill-Burton Act. It gave hospitals money for development (Longest, 1994). In exchange, hospitals committed to take care of indigent patients, as they needed it. Through this system, many SWPA Latinos obtain care for their illnesses, care for the illnesses of their children and also “well baby” care. This system allows them to get outpatient or inpatient care, bloodwork, and even

prescription medicines at no cost. The only requirement is that the patient write and sign a letter stating he or she had no other way of obtaining health care. After six months, the care is no longer available, but the arrangement can be renewed. No questions about immigration status are asked. During the data collection period, some changes affected this arrangement. Patients would have to demonstrate need, in terms of an income limit. This happened perhaps for two reasons. First, more uninsured people might have moved into SWPA, and second, a greater proportion than before might have become aware of this option. As more patients began using it, they might have become a financial burden to the hospital. The new limitations left without care those who were not officially defined as “poor,” but could not afford to be insured or to pay for health care on a fee-for-service basis, as well as those with an uncertain immigration status.

Other hospitals, such as West Penn, also offer free care; in some cases, users call these services the “Hill-Burton Clinic.” The same requirement of writing a letter stating that the patient has no other coverage for health care exists in all of them. Other types of formal arrangements include the use of neighborhood clinics, or reduced-cost clinics, such as Family Health Council or Alma Illery. The sponsor organization for Cuban refugees, often Catholic Charities, arranges housing and health services for them. These services are free, but available only for a short period of time. Some physicians accept patients at their homes or offices, at low or no cost. In several cases, doctors see Spanish monolingual patients unable to pay for services in their offices. Patients are often referred by an acquaintance who recommends the doctor.

Within the formal system, there is only one health program specifically for Latinos available in the community. It is run by Family Resources (FR), a non-profit organization with the primary goal of preventing child abuse. Occasionally, some other agencies offer services to Latinos, but not on a regular basis. Family Resources’ Latino Outreach, *Programa Para La Familia Latina*, operates under the assumption that keeping the family unit healthy and balanced prevents child abuse. It works primarily as a referral system and a “broker,” but does not offer direct health services. Other ways in which this program assists Latino families is by providing links to legal assistance and

nutritional programs, such as WIC. Additionally, they organize community activities, such as picnics and retreats, for people to get together. A Spanish-speaking Latina social worker is the only staff person for the program. This makes it easier for people to connect with her and build trust and rapport. Several lower income clients of the *programa* tend to relate to her in a rather personal way. They believe they receive some services directly from her and fail to connect the benefits with the agency. The program started with just a few clients and has grown considerably, filling an important need of the Hispanic population in Pittsburgh. Recently, the social worker has increased her hours with the program. More personnel are needed, but program funding cannot yet support more staff.

The *Programa Para La Familia Latina* has been responsible for many of the formal options arranged for Latinos. For example, the program tries to find a health insurance option for people in need. If that is not possible, it tries to provide them with another option, frequently at no cost, so they can get the health care they need. In another example FR arranged for outpatient care at Shadyside Hospital to be available for a limited time, by appointment. This arrangement was convenient, and some of the available doctors were Latinos, and at least one spoke Spanish. FR has also made the community aware of special opportunities, such as free vision screening, eyeglasses, and breast cancer screening. It is quite possible that FR was in part responsible for increasing Latino awareness of the “Hill Burton Clinic.”

Some Hispanics take advantage of the opportunity to go to the doctor when they travel to their countries of origin for vacations. A few have insurance in their countries, but no primary care provider in the U.S. Most people who use this arrangement, however, are not insured and go to care in their countries because it is cheaper. People resort to this arrangement for doctor’s visits, but much more frequently for dental care. Some even make appointments with their dentists in Latin America before leaving the U.S. This is not surprising, since dental insurance is not a benefit offered by most jobs, and, if provided, it tends to be partial. Additionally, dental care in Latin America is much more affordable. This may be why logistic regression did not show dental care to be affected by income or insurance status.

## 2. Who are the users of formal arrangements?

Most often people using formal arrangements are uninsured or are waiting for their insurance to be effective. They might be low-income people with few or many years of formal schooling. Others are people here temporarily. They usually cannot pay for health care any other way. Users need to be minimally connected to a network or to the formal system to be able to find the option that is right for them. As a matter of fact, several interviewees asked me how they could obtain free or low-cost care. I referred them to Family Resources.

## 3. What are the advantages and disadvantages of formal arrangements?

People tend to like these arrangements not only because they are offered at low or no cost, but also because some are close to home and many could see the same provider each visit, at least in some cases.

The disadvantages of these arrangements are that some of them do not cover comprehensive care, especially hospitalization, and many do not cover prescriptions. They might be one-time opportunities or short-lived offers. The patient has no usual source of health care and no guarantee of continued care. Additionally, some patients view their formal arrangement as some sort of charity care, and they perceive it to be low quality and undesirable. For example, several people used the University of Pittsburgh dental clinic for low cost care. Patients were seen by residents and students, and some thought it was low quality, because doctors-in-training were practicing on them. Additionally, some believe residents did dental work for academic purposes, even when it was not medically necessary. Others praised the quality of the University's dental service. I found no similar complaints in the case of medical visits.

## ***D. Informal arrangements***

### 1. Types of informal arrangements

Informal arrangements are ways of getting health care by circumventing the established health system. These arrangements include using of traditional western medicine and other kinds of cures. They are frequently free; they are commonly obtained through acquaintances or people who belong to a network. From one contact, another contact was called, then another one. These were the “links” of a “chain” that ended in the provider. The use of the network and the formation of the chain tended to involve personal relationships.

The most frequent type of informal arrangement is illustrated in this hypothetical example. Dr. Miranda receives a call from Elvira. Elvira might introduce herself as a cousin of Carlos, who is in turn an acquaintance of Josefina, who is an acquaintance of Dr. Miranda. Elvira requests Dr. Miranda care for a relative. After Dr. Miranda agrees to the consultation, he might see Elvira’ relative at the doctor’s home, often that same day. If the case appears to be very serious or to require urgent care, Dr. Miranda refers the patient to the emergency room.

There is typically no charge for the informal consultation and, occasionally, the doctor provides the patient with some free sample medication to start the recommended treatment. Frequently the doctor calls afterwards to check on the patient’s progress; in one case, the physician even drove the patient back to her home. Usually, this type of contact involves a physical examination. However, sometimes it is an incomplete one, and in some cases, it is just a telephone consultation. Many Latinos have referred this type of arrangement, involving several different physicians, frequently Latino ones. Since my husband is a physician, I had the opportunity to observe firsthand several of these informal encounters.

Most informal arrangements found in SWPA were very similar to Elvira’s hypothetical example, but others were somewhat different. A woman who lived in a house with seven other Latinos said she and her roommates used to see a Polish doctor who lived nearby and spoke some Spanish. His services were free. Some Cubans, who came as refugees, lived initially in temporary housing.

A Spanish-speaking American doctor approached some of them and offered his help if they needed any care. The doctor was very nice and did not charge them. An uninsured man usually consulted a doctor he saw at church about his health. The consultations took place right there, at the church, and they were free.

Other types of informal arrangements involve seeking care from nurses who can administer first aid or introduce the patient to the use of some facilities. For example, Rosina was treated for a cut at a place where a nurse friend of her son took her. The nurse was very nice, because she was a friend of Rosina's son. Other people went to the emergency room and asked acquaintances that worked in a health care setting for informal care. The care is usually free of charge, and the patient avoids registering at the hospital or medical center. A few Latinos have befriended some U.S. medical residents, so that, when necessary, they can obtain prescriptions from them. This is often provided without any examination of the patient. In several cases, people self-medicated themselves with over-the-counter medicines. It is not rare for people to use prescription drugs, such as antibiotics, that they had brought from their country of origin just for this kind of use. Finally, there were those who used other people's health insurance to get care. For example, one man used his sister's medical card to make an appointment.

Sometimes, people go to their country of origin for health care. Some go to get care from doctors, some from *curanderos*, and some both. A man who was involved in an accident needed treatment and decided that the best thing to do was to go back to Mexico for health care. Apparently, it was not a doctor's care. He admitted that one of the reasons he chose this course of action was that he had no insurance. He added there were other reasons, too, but he would not explain them. Sometimes, people who were initially here visiting for 6 or 8 months would use an informal arrangement when they became sick. In a few cases, the informal arrangement was not enough for them, and they needed X-Rays or blood tests. Then, they would cut their "visit" short and return to their country for care.

A very common informal arrangement in Latin America is to go to a pharmacy and ask the clerk for medicines. This arrangement is not found in

SWPA, perhaps because pharmacies are much more regulated and there are no herbal pharmacies tending to Latinos in this area.

Latino patients regard many of these informal arrangements as medical care, especially when they involve a doctor. Some of these arrangements might have been counted as such and been included in the percentage of Latinos who responded they had a visit to the doctor in the past year (almost 80%). This became evident when, after the interview, I asked participants for some clarification. Some of them had low income, were uninsured, spoke little or no English, and yet, they were “very satisfied” with their last visit to the doctor. They explained to me that they had contacted some people in their network and obtained care for free from a very nice doctor who spoke Spanish and did not charge them. Therefore, when we say that 20.2% of Latinos did not see a doctor in the past year, we are not counting those who saw a doctor in an informal way. The percentage of people who had no formal medical visit might be larger, but it is impossible to know how large. Since this issue was discovered through participant observation, it had not been included in the original survey design, and data on this issue were not systematically gathered.

## 2. Who are the users of informal arrangements?

People who resort to informal arrangements might be uninsured; in many cases identified during this study, they were. For them, informal arrangements might have been their only chance of obtaining health care. Some who were uninsured and had a formal arrangement, sometimes used informal ones, too. Even a few who did have insurance still resorted to an informal arrangement. This prompted the question of why they did so.

## 3. What are the advantages of informal arrangements?

People were generally satisfied with informal arrangements. They were usually free of charge, quick to access and are user-friendly. No bureaucracy or form filling was involved, and they were available at almost any time during the week.

Of course, reasons for using these arrangements varied. People who were uninsured might have been acutely sick, they might have been unable to stand

a chronic condition any more, or they might have needed a driver's license examination. Some people had health insurance, but they distrusted their provider. Therefore, they asked their friends who might be related to the health care system for advice, before or in place of contacting their PCP. Sometimes they could not find their primary care doctors on a weekend or late at night, and informal arrangements were quick solutions. A few users perceived informal arrangements as confidential. Women who were abused were sometimes referred informally to providers. For example, a 911 operator who knew a Latina provider gave her number to a caller. The provider helped the abused person over the phone on a voluntary basis. The woman was afraid to approach an agency, which would keep records of her case. For her, it was easier to relate to the provider referred by the 911 operator.

Perhaps many advantages of informal arrangements can be explained from the perspective of culture. These encounters tend to occur in a culturally appropriate and non-threatening environment, where trust and personalized care are more likely to occur than in the formal system. The provider is usually, though not always, a Latino, and the consultation is conducted in the language of preference for the user, frequently Spanish. This provider might also be more familiar with or share the particular cultural beliefs of the patient, and be able to relate to his/her explanations of disease and treatment expectations. Even when the provider is not a Latino, it is somebody who has made every effort at establishing good communication. Are these all the advantages of informal arrangements?

#### 4. Informal arrangements: drawing resources from culture

One feature of informal arrangements appears to benefit all users, regardless of income or insurance status. It might be a by-product of informal arrangements, but it is possible that it is one of the main reasons Latinos, consciously or unconsciously, use them. Informal arrangements take place in a family-like atmosphere. A personal relationship is the rule, as is the involvement of one or more persons. SWPA Latinos discuss their health problems with their friends and relatives when they call them. Several people are contacted to find a source of care, and they have the opportunity to give an

opinion about the best course of action. Later, a number of those contacts offer advice and support to the sick person. The illness episode stops being an individual issue and becomes an issue of the extended family or the fictive kin. Perhaps without consciously trying, Latinos are reproducing some important features of the way the cultural group handles illness and its treatment. These features fulfill Latinos' preference for having personal relationships with their doctors.

Family involvement in health decision-making is not surprising, since among Latinos and Latin Americans, illness is considered to be a family affair, instead of an individual one. The social network, especially the extended family, takes part in decision-making and in validating the illness (Bassford, 1995; Giachello, 1996 b; Garro, 1998; Saint-Germain & Longman, 1993). Once it is validated, the family offers a great deal of support (Bassford, 1995). This behavior is related to the trait of familism mentioned in the literature, as it involves many people in solving the problem (Marin, 1989; Marin & VanOss Marin, 1991). St. Germain and Longman (1993) found that for Mexican American women in Tucson, AZ, kin includes both family and fictive kin members. Illness is seen in a family context. The responses to illness include interpersonal relationships. The kin network interprets the symptoms, validates them and labels the illness. Once this is done, the sick person counts on the support of the network. The family not only takes part in the decision-making, but the network itself is instrumental in restoring physical and social balance. In Hartford, Connecticut, Schensul and Schensul (1982) found that reliance upon *compadres* (literally, parents of the godchild) and kin is a significant adaptive mechanism for negotiating entry into the health system, providing health education, consulting some specific problems and providing support such as baby-sitting, transportation and money. When economic resources are limited, human ones become more important, and psychological support is one of them. It is interesting that they compare their study with a previous one of Mexican Americans by Padilla and Salgado de Snyder (1992). Padilla and Salgado de Snyder found that Mexican Americans underuse the system because they can rely on an alternative system of kin. In Hartford, Schensul and Schensul say that at a time when resources are more abundant, the kin

network helps subjects use more resources within the formal system. In the same way, in SWPA, network members provide help with chores, such as cooking, baby-sitting, and driving; they also provide emotional and social support. For Latinos in SWPA, health decision-making is a social activity, and people talk about their health decisions, speculate about diagnosis and courses of action, and use more health care resources. As in Tucson, the network is active in restoring social balance.

Blackhall et al (1995) conducted a study in Los Angeles that included 200 people of each ethnicity: Korean American, European American, African American and Mexican American. They found that Korean Americans and Mexican Americans use a family-centered decision making style. The family is in charge of getting and processing bad news and making life and death decisions. In multivariate logistic regression, they found that both groups are less likely to favor telling the truth about diagnosis and prognosis in life threatening cases and also less likely to believe the patient should be the primary decision-maker as compared to European Americans. Lower SES is related to less truth telling; those more acculturated are more like European Americans. They conclude that family-centered decision-making is determined by ethnicity and, to a lesser extent, by socioeconomic status. They also mention that this same pattern has been reported among Chinese and Ethiopian families, and in other parts of the world, such as Greece, Italy, Japan and Eastern Europe. The ones that appear to be different from the norm are the European Americans. A study in Miami, by Caralis et al (1993), including African Americans, non-Hispanic Whites and Hispanics, found that Latinos are more likely to follow doctor's opinions in case of doubt, but that they are also more likely to choose a family proxy, rather than a doctor, to make decisions. Rivera-Tovar (2000) said that, in her experience, Latinos try to protect a patient suffering from a serious illness from loss of hope by not telling him or her about the diagnosis. Instead, it is the family that makes all the pertinent decisions. She explains this as being the result of familism and collectivism, with autonomy being perceived as a burden for the sick person. Therefore, the family has the duty to care for that person. DeSantis and Halberstein (1992) found

that Latinos in South Florida also prefer to incorporate family members in decision-making, but that health care providers often neglect this preference.

Do informal arrangements offer any advantages to providers? The provider, especially if he or she is a Latino, tends to accept the arrangement, from a sense of solidarity. If we were to accept communalism and *simpatía* as legitimate traits of Latinos, this response played well with them. It was the right thing to do following the cultural trait of communalism, which made it important to take care of the needs of others. The provider also acted within *simpatía*, or preference to having a pleasant relationship with others. Providers might not get any economic reward from this arrangement, but they might get a sense of having done the “right thing” and having gained respect from the patient and other individuals in the chain of people involved.

#### 5. Informal arrangements: A solution to Latino health care access problems?

Informal arrangements may look like a great alternative, but if we observe them more closely, we will find their disadvantages. First, they are unstable. If one of the persons in the chain of contacts leading to care is not available, the whole arrangement might fail. This is especially problematic in a mobile population that changes phone numbers and addresses frequently. In our example, the phone of cousin Carlos may be disconnected, leaving no way to contact Dr. Miranda.

Once the arrangement is set, there might also be risks involved, for both the patient and the provider. Typically, no record of these informal encounters was kept. This makes following the patient’s history more complicated, especially if the episode was not resolved or if the patient develops complications. It might also compromise continuity of care. Lack of comprehensive care is even more of a problem here than with formal arrangements. Usually, the provider has no means to perform any blood tests or X-Rays. The patient might face higher health risks, as advice might not be grounded in medical decision-making, even when involving a health professional. If the provider sees the patient without taking a proper history or giving an exam and not all the diagnostic or therapeutic possibilities are weighed, the patient might not receive high quality care. An example of a case

in which a person was misdiagnosed and risked complications is that of Teresa. She experienced pain in her leg and “decided” she had thrombophlebitis. She informally talked with doctors at a social occasion; they did not examine her. One of the doctors recommended some pills and made an appointment for a Doppler exam of Teresa’s lower extremities. She did not go to the appointment because she did not want to impose. When her pain worsened, she called an acquaintance, who was a pediatrician and told her to go to the emergency room. Teresa called me, instead. Finally, she followed our advice and went to the emergency room. Teresa had a heart problem, not thrombophlebitis. The leg pain was related to a chronic spine problem and excess weight. The initial informal arrangement had led to labeling her with a diagnosis that was wrong, putting her at further risk due to her cardiac condition.

Another example in which an informal arrangement led to delayed care was that of César. He “knew” he had a urinary tract infection, so he asked one of his medical resident friends to provide him with some ampicillin. The resident did not examine him. César took the antibiotic for a couple of weeks with no good results. He waited for 20 days, mainly because he feared not being able to pay for care, and, additionally, because he distrusted U.S. medical providers. Finally, he told another friend about his problem, and she referred César to an acquaintance, who happened to be a urologist. The doctor would charge a reasonable price. César went to a formal medical visit, informally arranged, and got treatment that cured him in a couple of days. In this case, due to the use of the first informal arrangement, César suffered longer and risked complications. However, he later obtained care that solved his problem within the formal system, using an informal referral. The manner in which the urologist was referred allowed César to trust him.

There are also some legal risks to informal arrangements that cannot be overlooked. The provider and the patient might perceive that the provider may not be accountable for any wrongdoing, as the advice might be part of a casual conversation. However, advice is given without taking into account possible liability. There are legal risks for professionals when they try to take care of problems outside their specialty. An example of this might be a dermatologist trying to care for a child’s asthma problem.

### ***E. How do people decide what system to use?***

Rogler (1983), while trying to explain underutilization of health services by Latinos, says that there are two theories. The first is based on alternative resources. Alternative resources include social organizations, such as extended family and non-family networks, and therapeutic options, such as folk medicine. The second theory is based on identifying barriers that do not allow Latinos to utilize health services. Barriers include poverty, language, prejudices, discrimination, and other cultural factors. Among cultural barriers, Rogler lists *personalismo*, *confianza* (trust), *respeto* (respect), *orgullo* (pride), fatalism, familism, and *machismo*. Here, I am not trying to explain underutilization, but rather why people would or would not use informal arrangements. In this respect, both theories might come together. SWPA Latinos confront barriers of various types and develop alternate resources to overcome or circumvent them. Curiously, many of the resources family and non-family networks helped arrange were within the biomedical belief system, just outside the formal health care delivery system. Also, several of the resources SWPA Latinos used to solve their access problems, such as *personalismo*, *confianza* (trust), *respeto* (respect), and familism, are among the barriers listed by Rogler. They are listed as barriers, Rogler says, because they tend to reinforce group-based face-to-face intimate relationships as opposed to more impersonal, bureaucratic, professional ones. However, if the established health system could adapt and incorporate the alternative resources, they would not be barriers. They could become tools for increasing utilization, and more importantly, for obtaining service satisfaction.

If the choice of informal arrangements is determined by culture, why do some Latinos decide to use an informal arrangement and others do not? This takes us to the field of decision-making. Garro (1998) summarizes types of decision-making studies and their weaknesses. Some studies are concerned with predicting behavior and others with explaining it. From an economic point of view, people are assumed to make decisions based on some rational process to maximize the value of the results of their decisions. They exercise “free choice.” However, some argue that this conceptualization diverts attention from

the broader historical, political and economical context in which decisions are supposed to take place, since many people's decisions are constrained by their situation. Based on her own work, Garro (1998 a and b) argues that human cognition is not fixed, but flexible and grounded in social and cultural processes. She says that emotions are not separated from this process, but rather they are a part of it.

People use their knowledge and feelings to make the choices they make and consider the situation they are in. Choices are not always the same and vary from person to person, because there is individual agency and because there is variation on the way each problem is processed through time. Matthews (1998) argues that normative decision-making models leave little room for individual agency, and that they do not work well when cultural rationality can tolerate ambiguity. Browner (1998) comments that, "...reasoning about health is not static, but instead continually incorporates new experiences and emergent information" (p.356). She adds,

"[t]he construct of culture is neither stable nor coterminous with well-defined entities such as ethnic groups or nation-states; rather it is a dynamic set of practices that informs but does not determine action".  
(p. 356)

Garro (1998) says that health-related decisions are neither completely determined by culture nor completely independent of it. They adapt personal and cultural knowledge to each problem posed, given real-world constraints. Additionally, the actual decision-making process changes with time in each individual. Given that Latinos in SWPA generally hold pluralistic beliefs about disease and therapy, to various degrees, it is quite likely that they draw from their diverse beliefs to solve each problem. An alternative set of beliefs can be seen as an alternative resource. If biomedical care is not available, then a home remedy may be useful. If a doctor could not be found through the system, then one may be found through the informal network. If the system does not offer a culturally acceptable option, an informal arrangement might be preferred. Also, if the informal arrangement is expected to yield more benefits than the doctor's visit, it would be preferred. For example, it is easy to imagine that someone could seek an informal arrangement and to see a doctor at his home for a skin

rash. It would be perceived as saving time and money, being in the language of choice, involving the family in decision-making and, of course, putting in motion social support mechanisms. However, if someone appears to have a serious, potentially life-threatening disease, it might be more likely for that person to access the formal system. At the same time, that person might seek social support by contacting his or her network and to decide whether the disease is severe enough, to determine the best place to go. In that way, he or she put in motion the social support mechanism.

These issues have not been studied here, but would be interesting material for future study. For a group that holds pluralistic beliefs, there might be no contradiction in searching for solutions to a problem in both the formal and informal network. The former, most would agree, offers the highest technology and appears to be regarded highly. The latter offers family involvement and social support, also regarded highly. If both sets of “goods” can be obtained from the same arrangement, that arrangement might be favored. This way of solving problems utilizes what has been called “social capital” (Israel, 1998), and might work outside the health care arena as well. Social capital addresses issues from a positive point of view and uses an ecological perspective.

#### ***F. What are the options for Latinos’ health care access?***

It is recognized that to change access to health care once and for all, better socioeconomic conditions are needed, as suggested by Vega and Amaro (1994). Soto Mas (1999) says that health care access barriers for Latinos will be erased when U.S. society understands Latinos as they are rather than something “special,” accepts their language, and facilitates fair job conditions and access to education. This might be true, but it will require a major societal change over many years.

Is there anything that can be done from inside the health arena? One of the objectives of a Latino health care agenda should surely be to increase the proportion of insured Latinos. For this, policy changes are needed, such as requiring all employers to provide health care as a benefit. However, Burciaga

Valdez et al (1993) and Hall et al (1999) warn about the risks of this solution. They say that a policy to cover only workers, would leave uninsured most children and women who do not work. Other risks they identify are making jobs more expensive for small businesses, possibly forcing them to close and resulting in a loss of jobs available to minorities. Alternatively, the cost could be passed to the employee, leaving them with an even smaller salary than before. Another solution proposed by Burciaga Valdez et al (1993) and Solis et al (1990) is broadening eligibility criteria for Medicaid or CHIP. Currently, many Latinos prefer to use the emergency room, because it might be “less costly” for them, if uninsured (Schensul and Schensul, 1982). Burciaga Valdez et al say that the preferred solution would be to institute a national health care system. This would result in net savings for the U.S. Unfortunately, attempts to pass such legislation in past decade have failed, and they are not generally being considered in political spheres at the moment. Even though does this appears to be the best option, the likelihood of a national health system being implemented in the U.S. in the near future is very small.

#### 1. Responding to cultural and language differences: adaptation

In response to language and cultural differences, what are the options for increasing health care access? Solutions mentioned in the literature may aim at changing the population or, as Saunders (1954) suggests in early work, acculturation. This means that the Latino population (or any other cultural group) has to adapt to the way health care is offered. Currently, nearly everybody would criticize such an approach as discriminatory. In addition, if the purpose of health services is to serve the clients, and if a large portion of the clients would welcome a change, it would make sense to advocate for such change. Traditionally, it is the system of health care that is seen as the norm, and those who have not adapted to it are seen as the problem. In reality, a sensitive health care system has to be able to accommodate a great variety of individuals. Friedl (1978) said

“A comprehensive health care model must include the flexibility and adaptability to incorporate human, cultural, and social differences

if it is to be effective in the delivery of health care to an heterogeneous population”. (p. 1)

Most people recommend the availability of bilingual, bicultural materials and interpreters to solve language barriers. Others advocate for increasing the number of Latino health providers (Carrillo 1999, DeSantis and Halberstein 1992, Polednak 1996, Riedel 1998, Sherraden and Barrera 1995, Solis et al 1993). Carrillo et al (1999) say that the provider needs to understand the meaning of illness for the patient. Therefore, they suggest curriculum changes for students of the health professions, geared to sensitize them to different cultures. DeSantis and Halberstein (1992), Sherraden and Barrera (1995), and Riedel (1998) recommend increasing sensitivity of current medical staff to cultural diversity through training. Talking about Appalachian migrants, Friedl concluded in 1978 that a health team approach looking at the patient as a whole is a good approach. He argued that, to promote better understanding and tolerance between Appalachian and mainstream culture, it would be useful to involve as many Appalachians as possible in health care delivery. Likewise, hiring more Latino health care providers would help in the sensitization of all health care staff.

The Bureau of Primary Health Care of the Department of Health and Human Services (1999), describes cultural competence as a requirement for all health programs. Cultural competence is defined as “a set of academic and interpersonal skills that allow individuals to increase their understanding and appreciation of cultural differences and similarities within, among and between groups.” This might include, as stated by Carrillo et al (1999) the tools of “good doctoring,” these are “listening, asking the right questions and meeting the patients where they are” (p. 833). In the case of Latinos, and perhaps many other groups too, this would also include enhancing the interpersonal aspects of the physician–patient relationship. Langer (1999) recommends that culturally competent providers approach care from the patient’s definition of the health problem. He also recommends that the foundation of care should be trust and empathy.

Polednak (1996) suggests that better standardization of physicians’ recommendations would aid in avoiding unequal treatment of patients based on

race or ethnicity. DeSantis and Halberstein (1992) boldly advocate for referring patients with folk syndromes to folk healers. Additionally, general changes that would benefit all clients and not just non-mainstream cultural groups include better schedules and availability of transportation (Riedel, 1998).

## 2. Knowing the community

It is almost universal to recommend that health care providers get to know the community being served and its culture before initiating any health program (Riedel, 1998). Balcazar et al (1995) proposed a method to tailor programs according to the specific level of acculturation and education of the target group. This makes sense, but it is still important to remember that acculturation does not completely represent culture.

Baker et al (1997) present a model called Latino Health Advocacy Program that has the goal of improving health care access and utilization among Latinos. Even though they say they tried to build on community resources, they discouraged “depending on reciprocal relationships in which people do things for each other” (p. 500) and encouraged more reliance on the system. They believe interdependence leads to individuals depending on others, rather than being empowered to act on their own. Therefore, they challenged community norms and tried to change community practices, but they say little about making the system more responsive to Latino culture. They said results were encouraging, but they fail to present any clear data. As described by Ruiz (1995), interdependence is highly valued among Latinos. The approach of Baker et al attacks the very foundation of Latino culture, as it encourages individualism and discourages communalism.

Sherraden and Barrera (1996) studied Mexican American women and concluded that since Mexican Americans have relatively good maternal child outcomes, existing positive prenatal practices of Mexican women should be encouraged. However, it is not clear what exactly those practices are. Perhaps more research is needed in this area.

Langer (1999) argues that culturally competent health care should be approached from a holistic point of view, concentrating more on the person and less on the condition. Cultural competence is critical in the care of chronic

diseases, because a trusting and lasting relationship is crucial for the success of care. Langer describes a program for Hispanic Americans in San Antonio, Texas, and African Americans in the Bronx. It consisted of using constructive, non-aggressive criticism to encourage behavior modification and coping skills. The approach enhanced positive interaction between patient and provider, regardless of ethnicity.

### 3. Incorporating culture: communal interest, family involvement and personal relationships

Some programs have been based on the characteristics of Latinos. One of the characteristics of Latinos that can be used to their own advantage, as a community resource, is what the literature calls *communalism*. Another is involvement of the extended family and fictive kin in health matters, which, as seen both in study data and the literature, is usual for Latinos.

Fulton et al (1995) describe a successful program in Rhode Island that was developed with community support. That program used the importance of families and of putting other people's interests first to promote cancer screening for women. The posters used Latina models and read "*Cuidar de ellos...significa cuidar de si misma*" ("To take care of them means...to take care of oneself"). The family orientation of Latinos is one of the major strengths of this group.

Benmanyor et al (1997) found in their research on an educational group for women that they obtained their strength and drive from their roles as mothers and wives. The women worked together in a literacy program emphasizing collectivism (working for a common goal) while developing unique individual capacities. Reaffirming collectivism, shared values and a collective form of organization enabled women to function better than they did in individualistic terms. The same could be applied to health programs that use extended kin networks. In Hartford, Connecticut, Singer et al (1993) developed a program for AIDS prevention aimed at Latinas, called *Comunidad y Responsabilidad* ("Community and Responsibility"). It was centered on cultural values that they had researched for several years, such as *reunión* (reunion), *responsabilidad* (responsibility), *comunidad* (community), and *personalismo*. Community women were trained as health educators with a focus on their responsibility for their

community and the contribution they could make to the common good. Women met in non-formal settings to exchange information and experiences in a personal way. By the end of the project most participants showed an enhanced level of awareness about AIDS as well as an increased level of self-efficacy. For the women who were the primary focus of the project, the groups became a major source of support.

Utilizing the family and social networks has been advocated time and again. Pérez-Stable (1987) sees the extended family as the ideal way to motivate health behavior changes. The problem, Schensul and Schensul (1982) say, is that providers tend to focus on the specific health services and see a family that comes with the patient as a source of trouble and interruption. However, if they focus more on the community, they can see that the family can be a resource crucial to obtaining social and material support for the patient. Rivera-Tovar (2000) believes that the family members who come with patients are not just company; the family has to be considered before important decisions are made. Then, they are ready to offer emotional and support.

Interestingly, Latinos are said to use more preventive services when they have a traditional Latino extended family (Suarez, 1994). This might be due to more availability of resources, such as child care, or to the availability of more support and/or advice. It has been said repeatedly that concerned relatives and friends can influence behaviors and should be taken into account when designing programs to increase use of preventive services (St. Germain & Longman, 1993; Marin, 1989; Fulton et al, 1995). The importance of the family has also been used as a reason to prompt women to seek preventive services. Saint-Germain and Longman (1993) believe that the family is underutilized as a resource to promote cancer screening and that siblings or adult children can play a central role. Freidenberg and Hammer (1998) add that relatives are usually seen by health care providers, but that non-kin networks that play a key role for elderly East Harlem Latinos, are usually overlooked. More attention should be paid to these types of networks. In contrast to these findings, Dietz (1997) found, in a study of the National Survey of Elderly People, that elderly people living with their children are less likely than those living alone to receive any sort of formal assistance. Their interpretation of these findings is that

children of elderly people do not act as “brokers” between their parents and the formal system. Ruiz (1995) and DeSantis and Halberstein (1992) advocate for use of extended family network specifically for mental health services. According to Ruiz, every member of the extended family has a symbolic function, and members are interdependent. Therapeutic efforts that aim at helping the patient to become independent often fail because they introduce yet another distortion in the patient’s system of life. He proposes a therapy that involves the family at all steps and aims at achieving interdependence of patient and family. Freidenberg and Hammer (1998) hit the spot when they say that finding the right mix between formal and informal structures includes acknowledging the services provided by a modified version of the extended family.

Another important way of making health services more attuned to Latinos belief system is to allow for a family-centered decision-making process, as suggested by Rivera-Tovar (2000) and Blackhall et al (1995). Ideally, patients might be able to choose whether they would prefer their families to be in charge of decisions about life-threatening diseases. If the patient chooses a family-centered model, then individual rights would have been honored while the cultural norm is respected. According to DeSantis and Halberstein (1992), acknowledging and accepting a family-centered decision-making model would also go a long way in adding a more personal orientation to health care.

#### 4. Community participation

Many authors now advocate for community based programs (Vega & Amaro, 1994; Riedel, 1998; Quesada, 1976; Polednak, 1996; Fulton et al, 1995). Community participation can take several forms. For Krauss et al (1997) it means that there would be representatives of the community helping to develop informational materials to use. For others it means that community representatives would act as teachers and consultants for programs (Quesada, 1976). Riedel (1998) says that health promoters from the community can be trained to work in their community. Carrillo et al (1999) believes that members of the community can do more than help implement the program. The parts, he says, provider and community, have to agree to a course of action. Balcazar et

al (1999) present an example of a program that integrates several culturally appropriate strategies in its design. The program aims at preventing heart disease and focuses on the individual, the family and the community. First, the program leaders learn about the needs of Latinos regarding cardiovascular health, construct a demographic profile of the target community, hold interviews with community leaders and conduct focus groups with consumers to learn about preferences and needs. Second, they build an *Alianza Comunitaria* (Community Alliance) including community leaders in health, education and the media, that become a part of program decision-making. Third, they launch a campaign that includes sports events, fairs, cooking classes, conferences, discussions, use of bilingual material, local youth distributing flyers, local health promoters, a poster designed by a Latino artist, and a “*fotonovela*”-like pamphlet (printed soap opera) about the Ramírez family and their heart health. Additionally, popular radio and TV programs stress the message, as do televised cooking classes. Most subjects interviewed after the program showed increased knowledge about cardiovascular health and were satisfied with the program; 70% of them had shared the materials and information with family and friends.

Vega and Amaro (1994) say that “these tactics must be implemented creatively, drawing on the aesthetic and spiritual qualities of Hispanic families and communities” (p. 61). They add, citing Muñoz, that “there is nothing intrinsic to Hispanic culture to suggest a lesser concern with health issues or innate resistance to interventions” (p. 62).

All of the changes described are positive. However, one very important action to be taken is for communities to take responsibility and interest in their own health matters, as advocated by Vega and Amaro (1994). The community itself has to engage in problem definition and problem solving to provide for lasting effective solutions, as noted by DeSantis (1998). The Hispanic community has to take the lead, be creative and show the system how to change in a way that is responsive to Hispanic tastes and needs. In the same way, Trueba (1999) talks about education and advocates empowerment. He says that understanding one’s subordinate and oppressed position is not the

solution, but it is a precondition to being able to face and change the system successfully.

A Latino national health agenda might sound like a difficult goal to achieve, since there is great heterogeneity among the group. However, there are some common points, such as insurance status, language, family orientation and preference for personal relationships. As Furino and Sumaya (1992) say, Latinos have much more to gain than to lose from such efforts, especially in terms of political power, if they stick together.

What should a local health care agenda look like? For the moment, perhaps the most likely actions to be taken are those that Latino health care professionals can carry out. For example, they may bring to the attention of local health care officers various needs of their population (i.e., translators, consideration of the extended family in health care). To be able to do this, people need to be informed and willing to discuss issues of health care access. Additionally, they have to be able to see the importance of keeping the community healthy as a benefit for all, not only for the poor. Only then can some of the socioeconomic barriers be overcome, and a common agenda be advocated. One necessary task is the development of a cohesive community. For that, different groups need to come together, put aside their differences – especially their socioeconomic divisions – and work on a common agenda. Eventually, as the community grows, grassroots groups may take the lead. These changes may, however, take several years to develop.

### ***G. Summary***

Those Latinos in SWPA who have no health insurance and cannot pay for care upfront, have to adapt to find a different way to access care. As have Latinos elsewhere in the U.S., many of them have used their social, mostly ethnic networks, which they have built in this area. The role of women in these networks is prominent among Latino groups elsewhere in the U.S. More research would be needed to understand fully the way networks operate in SWPA. Some Latinos, however, are unable to use this resource, not being connected to a significant group of people, as a result of living in an area that

has no cohesive Latino community. Some Latinos make formal arrangements, that is, they find ways to obtain free or reduced cost care within the formal system. Many of these arrangements are facilitated by a Latina social worker that works at a local non-for-profit agency. Several local hospitals offer free care to low-income residents. However, recently these options have become more restricted, leaving those who are poor, but escape the official definition of poverty, without an affordable source of care.

Many other Latinos develop informal arrangements as ways of getting health care outside the formal health care system. Typically, informal arrangements are arranged through a chain of people. Most of these arrangements are prompt, free, and in the language of choice of the patient. Most of the users are uninsured. However, some of them do have health insurance. Apparently, an additional advantage of informal arrangements, one that has prompted even insured individuals to use them, is the involvement of several people, who are members of the “chain.” They are often part of a close network and operate as an extended family. They take part in health care decision-making and support the sick person socially, emotionally, and materially. Latino doctors involved in these arrangements obtain a sense of doing the right thing and are able to see their prestige among Latinos in SWPA enhanced. These arrangements rely on the concepts of familism, *personalismo* and communalism, found in Latino groups throughout the U.S.

Informal arrangements, as a creative way to get care, are advantageous, but have drawbacks. The chain of people involved makes them unstable. Once they are set up, their informal nature leads some social contacts to be regarded by users as health care contacts. In most cases, physicians do not have the necessary facilities to perform auxiliary tests, and a patient might be misdiagnosed. Additionally, providers and patients do not realize that there are some legal risks. Therefore, informal arrangements cannot replace equitable access to the health care system. However, some features, such as family involvement, personal relationships and community orientation, can be included in regular health care for Latinos.

Latinos are able to draw from their pluralistic beliefs to find these arrangements. Many of the arrangements used are within the biomedical health

care system, but other options are often considered and sometimes used. Some arrangements could combine the high technology of biomedical care and the cultural appropriateness of informal care. In their decision about which approach to take, Latinos appear to draw from their cultural background and their new environment. The approaches vary according to the individual, the problem, and the particular circumstances. Decision-making in this population, and in other Latino groups, should be studied further.

The best option for enhancing access to health care would be to achieve an equitable society, where everybody has equal opportunities. Options within the health system are of two types: adapting the population to the system as is, and making changes that would adapt the system to the populations served. The latter would include providing bilingual materials, translators and bilingual providers, knowing the community before starting any programs, including community members in the decision-making process, and training staff in cultural competence. In the literature, some authors advocate for including particular Latino values in their care, particularly sense of community, family – or fictive kin– networks, and personal relationships. These values, if seen as resources, could become tools for more effective health care. All of these improvements could be attempted by the health system alone. However, they would be more likely to succeed if the community itself took the lead in identifying those changes its members consider to be necessary, as well as in the process of shaping those changes. For this to work, however, a cohesive community that is capable of standing up for the interests of the group would have to develop.

## **IX. Summary, conclusions, and recommendations**

### **A. Introduction**

Sometimes fictional literature offers a good description of a people's cultural beliefs and behaviors. In “*La Mujer de la Frontera*” (“The Woman of the Border”), Eduardo González Viaña (1996) tells the story of Doña Asunción, a Guatemalan woman who travels to Mexico and crosses the border illegally to find a medical doctor in the U.S. to treat her son, who has an incurable disease. Doña Asunción believes it is the will of God that her son be cured, and she has to help that happen. She holds pluralistic beliefs, as she believes doctors, especially U.S. doctors, are the best option for her son’s treatment. However, she also relies in *curanderos* (medicine men), mediums, and what she reads in *Selecciones* (Reader’s Digest). On one occasion, she is treated for free by a Cuban doctor and friend of the family in whose house she is staying. As Doña Asunción travels north, she makes friends with Latinos from various origins and becomes part of one of the families. Then, the whole extended family and some close friends of the family try to decide which would be the best cure for Doña Asunción's son. They also help her to find care from a range of diverse providers, from doctors to *curanderos* to mediums. Of course, Doña Asunción’s son has no health insurance, and she is not sure what health insurance is. She is convinced she can pay for services in kind; for that purpose, she brings her wedding ring with her.

The story illustrates several points of conflict between Doña Asunción’s concepts and practices and the concepts and practices of the U.S. health system. Many of those conflicts might be pervasive among all Latinos, and some are very similar to what I encountered in southwestern Pennsylvania (SWPA). It

also illustrates family involvement both in health care decision-making, and in setting up formal and informal arrangements for care, such as the ones identified in SWPA.

### ***B. Overview of the study and limitations***

Access has been defined as “those dimensions which define the potential and actual entry of a given population group to the health care delivery system” (Aday et al, 1984, p. 13). Latinos are at a disadvantage when it comes to accessing health care, as compared to other groups in the U.S. For example, Latinos are the ethnic group with the largest proportion of people without any health insurance, and they are the largest proportion of people who did not see doctor in the past year.

The conceptual framework for this research was Andersen’s 1995 model for health care access. In this model, use of health services affects outcomes; characteristics of the population, health behavior, and health practices are factors that determine use of health services. Outcomes are health status and satisfaction. They may, in turn, affect the determinants of access. The model explicitly includes a dimension that contains the health care system and the external environment. They can affect health behaviors, health outcomes, and predisposing characteristics of the individual or population, such as income or education. Driven by this feature of the framework, and in an attempt to understand the factors that affect access with a broader perspective, a community description was developed to serve as a backdrop for the survey results.

Access can be divided into two dimensions, potential and realized. Potential access relates to the process of obtaining health care or, said differently, to the presence of enabling resources for health care utilization. They are, for example, health insurance and a regular source of care. Realized access refers to actual services used. Following Andersen’s (1995) updated framework for the study of access, dimensions of potential access were conceptualized as determinants of realized access.

Southwestern Pennsylvania (SWPA) was defined for this study as a geographic area, including seven counties: Allegheny, Beaver, Butler, Fayette, Greene, Washington, and Westmoreland. This area has traditionally had a small Latino population. The Latino population in SWPA has been increasing, but data on their health care access are virtually non-existent.

This study was undertaken from the point of view of social justice, which draws from utilitarianism and focuses on the common good. According to a social justice perspective, health care access should be distributed equitably among all. This means that everybody should have potential access to care, and realized access should be determined by need, rather than by characteristics of the social structure. Given that available data at the national level shows that minorities and the poor have inequitable access to care, it was hypothesized that access to health care for Latinos in SWPA was not equitable. Most studies on access to health care focus on its financial determinants. However, culture and language also appear to determine health care access, though they have not been widely studied. The objectives of this study were

- 1) To investigate the relationship of financial, cultural and language factors to potential and realized access to health care for Latinos in SWPA, and
- 2) To understand the characteristics of cultural and language barriers to health care for this population.

A combination of quantitative and qualitative techniques has been proposed as appropriate for research with Latino populations, and it was used in this study. Participant observation with Latinos in SWPA was used to construct a sampling frame of this population, develop a comprehensive description of their community, and explore in detail the characteristics of language and cultural barriers to health care, as experienced by them. A face-to-face structured bilingual survey was conducted on a sample of 206 Latino adults. Analysis of survey data included construction of estimates and logistic regression.

The limitations of the analysis include a limited sampling frame and the relatively small sample interviewed for the survey. To balance these limitations, special efforts were made to include in the sampling frame a diverse range of

individuals, and results were weighted to decrease the influence of bias. Additionally, participant observation served to complement quantitative data, as it included informal conversations with a larger number of people. The limitations of the sample decreased the power of the study. Therefore, the absence of a significant association should be taken with caution.

### ***C. Discussion of the findings***

#### 1. The social context

There have been Latinos in SWPA for more than 80 years, but the population has been always small. Early this century, most of them worked in the mills and railroads. As time passed, industry in the area downsized, and few additional blue-collar immigrants arrived. The universities, however, attracted students and professionals, many of whom decided to stay in SWPA. As a result, Latinos in SWPA have been, on average, a group with many years of formal schooling. During the past ten years, service workers –many with few years of formal schooling– began arriving in SWPA in greater numbers, and this trend has continued. At the time of this study, the population is mixed, with the number of immigrants with fewer years of formal schooling increasing faster than the number with many years of formal schooling. Latinos are employed in many types of occupations, ranging from managerial and professional services to agriculture. Due to immigration status, certification issues, and not enough English proficiency, their income is not generally high, even among those with many years of formal schooling. Many professionals work odd jobs, some in the service sector. Jobs and income are not equitably distributed. This important finding helps us put into perspective the findings about health care access, and it is related to the external environment, that, in Andersen’s model, influences predisposing characteristics and enabling resources of the population.

What does it mean to be Latino in SWPA? Latinos in this area, as in other areas in the U.S., have a sense of ethnic identification, although the name, shape, and exact characteristics of the group with which they identify are not clear. Latinos are connected to each other through traditions (i.e., food and music), their concept of family, and language. Perhaps more important

than this is their appreciation of extended family relationships. Those who are able tend to bring their families to the area as soon as possible. Those who have no families here build networks of people that operate like extended families. Networks exchanged information and support. The places they connected were usually church services, festivals and social gatherings. Being a heterogeneous group with members from many countries and of different backgrounds poses a challenge for the construction of identity. There may not be a clear source of identification, but invariably there was a need to be similar to someone else, even if the most easily noticed similarities, such as language, were lost after several generations in the U.S. According to Silvestrini (1997), culture is not language, religion, arts, or history, but rather a little bit of each. She says, "Culture gives a sense of unity, connectedness, a vision of our identity" (p. 43).

Being Latino in SWPA also means living in a community with contrasts and facing discrimination from Anglos and in many cases, from other Latinos. Latinos in SWPA are geographically scattered, and although their population is growing in numbers, it is still small. They are divided by several factors, but socioeconomic differences are the greatest divisions. There are literally, two groups of people: those with few years of formal schooling and those with many years of formal schooling. Since income tends not to be commensurate with education, some people who consider themselves to be middle class try to underscore their social status by highlighting their educational achievements, hoping to clearly differentiate themselves from those with less formal education. This attitude creates conflicts and leads to social inaction. Additionally, the loose organization of SWPA Latinos was the result of being a small population with a large proportion of people of middle class extraction, who are usually less exposed to pressing material needs that prompt groups of people to organize. Some Latinos are isolated from each other not by choice, but because they are unable find each other. Not being a cohesive community has implications for health and health care. We may say that, in the late 1990s, Latinos in SWPA comprised a group of overlapping communities and, for many, represented the hope of a more cohesive whole. Just as the identity and boundaries of the U.S. Latino community are in a process of change, the Latino community in SWPA is not well defined, and it is actively changing.

## 2. Health and health beliefs

In general, Latinos consider themselves to be healthy, although many have concerns related to mental health issues, especially isolation. Regardless of educational level, Latinos tend to believe in health as a holistic concept, where body and mind are one entity. They hold pluralistic beliefs regarding health and health care. Most of them adhere to biomedical explanations of disease. At the same time, many consider alternative explanations and cures, such as those derived from humoral theories of health to be valid and do not see any contradiction among the different sets of beliefs.

## 3. Potential access to health care

There are differences in health care access by income, and many cultural issues and language differences pose barriers to health care access in SWPA. Therefore, according to social justice, access cannot be considered equitable. Income has a greater impact on potential health care access, and the impact of culture is greater on realized health care access.

Interestingly, although the Latino population in SWPA is perceived to be middle class and to have many years of formal schooling, the proportions of individuals who are uninsured (38.1%) and have no regular source of care (20.2%) are not significantly different from those of Latinos at the national level. This might be explained by a characteristic of the social structure: income is low in relation to years of education.

The main determinants of potential access are socioeconomic. Income and education determine having health insurance, most likely through the type of job the individual has. Income determines having a regular source of care through insurance status. Qualitative data shows that many individuals hold jobs that do not offer health insurance as a fringe benefit. Many others can start using their health insurance only after several months of employment. Job instability resulted in many people who qualify for insurance spend long periods of time uninsured. Occasionally, the spouse or children of the worker are not covered, or preventive care is not included in the plan. Some people qualify for Medicaid, but would lose that benefit if they worked. As a result, they

do not work, or they risk losing their benefits by working “under the table.” For those who have been in the U.S. fewer than 5 years, income is more important in determining having a regular source of care than for those who were in the U.S. for a longer time.

Some Latinos in SWPA choose to go without insurance, or without a regular source of care, as they consider themselves healthy. However, this was not really a choice; the people who “chose” not to buy insurance could not buy it. To complicate matters further, lack of information meant people were unable to make the best of their situation. Some Latinos trusted God or their luck to protect them from illness until they could obtain health insurance. In those cases, being healthy was more of a hope than a reason for not having insurance. Often, people waited until they could get covered care or until they were extremely sick and could not delay seeking care any longer. As a result, preventive services and dental care are the ones postponed more often.

#### 4. Realized access to health care

Several informants mentioned difficulties caused by paying for care or losing salary because of doctors' visits. However, financial factors were not the most important determinants of realized access. Income did not determine whether or not a person saw a doctor or a dentist in SWPA. The proportion of those who had no visit to the dentist during the past year was 33.0%, smaller than the proportion of Latinos who did not at the national level. The proportion of Latinos in SWPA who did not see a doctor in the past year (20.2%) was similar to national data. However, in order for access to doctors' visits to be considered equitable, it would have to be determined by need. Having a regular source of care determined utilization of services, but physical health status, mental health status, and age were not determinants of realized access. Sex determined utilization of doctors' visits; women saw doctors more often, as happens with all population groups. This result might be due to greater need for care on the part of women, but it might also be due to less cultural acceptance of seeking care on the part of men. Additionally, to speak of equity we would have to consider quality of care and any differences in the distribution of services by cultural variables. Qualitative data show it was not equitable.

Realized access is affected more than potential access by cultural differences. The most obvious of these is language. Informants reported there were no regular translators at most doctor's visits. However, many Latino professionals believed there to be translators for every contact. This is an example of how socioeconomic divisions affect opinions and information. Some professionals are either not aware or choose not to be aware of the recent influx of Latino immigrants with few years of formal schooling and low English proficiency. This is also an example of how misinformation of health professionals about this problem does not allow them to act upon it. Translation is only one aspect of the importance of language in communication about health care. Language also reflects culture, and sometimes expressions cannot be translated. Additionally, Latino patients –including those who were proficient in English– feel that they need to talk to a Spanish speaking person when they are sick; translation is not enough.

A second cultural theme that emerges as affecting realized access is the preference for relationships with providers to be personal and warm. The provider's commitment and interest are at least as important –and perhaps more important– than his or her medical knowledge. This is similar to what was observed in other immigrants groups to the U.S. (Kraut, 1990). The biomedical system promotes impersonal relationships and imposes time restrictions that clients perceive as signifying lower quality of care. Latinos value providers that take their individual situations into account when conveying information to them and treat them as “human beings”.

Some Latinos are convinced that they have received substandard medical treatment because of their ethnicity. This could not be proven, but it has been demonstrated previously that African Americans receive different treatment due to ethnicity, and, therefore, these concerns have to be taken into account. Discrimination plays a role in making health care less effective and/or less frequently used.

Participants' evaluation of their health care visits has affected later use. This result is in concordance with Andersen's model. Those who had a negative experience with the health system, due to financial and administrative barriers, language and cultural incompatibility or discrimination, avoided later use as

much as they could. When an individual's perceived barriers were insurmountable, that individual would not seek health care. The actual use of health services would depend on several factors: severity of disease, health insurance status, ability to find culturally compatible care, being able to afford care, being able to communicate in English, perception of discrimination in the health care system as widespread, consideration of preventive care as a high priority, and ability to connect with a network that provided information and support. These factors affect all contacts with the health care system, but understandably, preventive care is most easily forgone, because skipping preventive services does not have immediate consequences. If the visit itself was expected to cause more distress than the perceived risk of illness, preventive care is not sought. This type of behavior has been found of other populations, not just Latinos. For example, Friedl (1978), who studied Appalachians more than 20 years ago, found not much difference between the perceived susceptibility to illness and perceived seriousness of the illness between Appalachian migrants and non-Appalachians. However, he found that Appalachians perceive treatment to be less effective and more difficult to get. They have to overcome so many barriers to action and so many within the health system, that they need to have severe symptoms to attempt to contact the health system.

Several Latinos who would use the health care system are unable to understand English-language instructions. Others would distrust their providers, leading to lack of compliance with recommendations and limited follow up. Finally, all these unsolved issues would add stress to the medical encounter, further affecting satisfaction, and, more importantly, the health of the client.

##### 5. Strategies to overcome barriers to health care access

As explained above, financial characteristics did not affect realized access as expected. This result is puzzling, but the explanation can be found in the qualitative data, in the informal arrangements that were attained through the use of social networks. Participants who were satisfied with every aspect of their last visit to the doctor, yet had no insurance and had low income, were asked

how they arranged their care. Most of them reported using informal arrangements. Circumventing the formal system, they found care through a chain of individuals in their social network. This care was prompt, free, and in their language of choice. Closer attention to these arrangements revealed that their use is widespread, and that even some people with insurance use them.

Those who are uninsured might use informal arrangements as their only way to get care. Those who have other formal arrangements or insurance might do so because it saves time. One of the cultural advantages of informal arrangements benefits all users, and that is they allow for the involvement of the extended family (or fictive kin) in all aspects of health care decision-making and health care. They provide validation for disease status, guidance, and emotional, social and material support. The family (or fictive kin) is often an integral part of health decision-making, support of the sick person, and recovery.

Informal arrangements are a creative way to obtain affordable and culturally acceptable care by using community resources. These arrangements are acceptable to both providers and patients. The loose organization of the community was an obstacle for many who needed to find suitable arrangements and obtain the necessary social and material support.

Even though informal arrangements are valuable resources of the community, there are many risks involved, some of which could seriously jeopardize the patient's health, including the instability of the arrangements or the absence of any standards to measure quality of care. Therefore, these informal resources cannot be considered to be a replacement for equitable access to health insurance, interpreters, and/or culturally appropriate care.

Given that Latinos in SWPA have pluralistic beliefs about disease and therapy in various degrees, it is quite likely that they draw from their diverse beliefs and their available resources to solve problems. An alternative set of beliefs can be seen as an alternative resource. If biomedical care is not available, then a home remedy may be useful. The widespread use of these arrangements might explain why several low-income uninsured people with no regular source of care were very satisfied with their last visit to the doctor. How exactly the decisions to use informal arrangements are made appears to be

related to each particular problem, the situation of the person seeking care and the external environment. However, further research could clarify this point.

Being a non-cohesive community affects health in that it decreases the available resources that Latinos who arrive in the area are able to find to help them cope with stress, build a network, and feel connected. Feelings of isolation can lead people to depression and put them at risk of other mental illnesses. Being a non-cohesive community affects health care access in several ways. First, the pool of resources for alternative arrangements, either formal or informal, is small. Second, those small resources are more difficult to find. Third, loose organization in the absence of ethnic solidarity precludes actions in favor of the group, such as requesting translators that are required by the Civil Rights Act of 1964 or petitioning a reach out program to inform and assist this population.

#### ***D. What are the options to solve health care access disparities?***

Results from this research show that potential and realized access to health care are not equitable for Latinos in SWPA, as they tend to depend on characteristics of the social structure, such as income, language, culture, and discrimination, rather than on need. The greatest problem Latinos in SWPA face to get care is lack of insurance, which might be related to low socioeconomic status, fragile immigration situation, and/or low English proficiency. Therefore, the inequalities stem in large part from socioeconomic inequalities that should be addressed, so that every person has the same opportunities. Regarding access to health care, insurance status might be the first problem to worry about. However, even if all people had health insurance, if no attention was given to other issues, there would still be a large access gap. This is in concordance with the literature and tells us that potential access to health care is not equitable.

The paradigms that inform health care services research are distributive justice, social justice, and deliberative justice. Distributive justice focuses on individual values and individual rights. Social justice focuses on community values and the interest of all (Aday et al, 1998). From an egalitarian perspective,

all individuals are of the same worth and ought to be treated equally. However, the social justice point of view is often criticized for having a top-down approach, resulting in the imposition of measures deemed good for all by a group of experts on to a population that may not share the same ideals and values. Aday et al (1998) say that deliberative justice is a concept proposed by Habermas to synthesize both liberal and communitarian approaches. It is based on fundamental democratic ideals and emphasizes participation in decision-making by those affected by the decisions.

According to the third paradigm, deliberative justice, communication between the interested parties is the basis for defining problems and finding solutions for those problems. Communication is directed to understanding each other's values and priorities; there is no value in imposing norms or values, even when they come from experts in the field. To be effective, a communication strategy has to be able build trust and collaboration, which is key to the success of this approach. This process may take time, but it can be useful for achieving culturally competent care, forming doctor-patient relationships, and achieving full participation of the affected population. Therefore, elements of both social justice and deliberative justice, and not just distributive justice, are necessary in order for health disparities among population subgroups to be decreased.

In the case of Latinos in SWPA, we need to move from the concept of distributive justice to that of social justice and strive to achieve an equitable distribution of potential and realized access. Many of the ways in which Latinos solve their problems, the explanations they give for their actions, and the insights about their beliefs may help us offer health care that is more responsive to their needs than it is now. Two features that can be integrated to improve the health care system are community orientation and involvement of the extended family. Health care delivery organizations can be more responsive to cultural needs by requiring training in cultural competence for their providers and by providing translators to non-English speaking patients.

However, actions would be more effective, and results would better respond to the needs of the population if we moved beyond social justice to consider deliberative justice approach. In this approach, the population affected

contributes to the planning and implementation of its care, expressing needs and on its own terms and with its own values. The Latino population of SWPA has not yet organized for the betterment of health care conditions for themselves, partly because they are loosely organized, and partly because they do not constitute one community. Latino health providers are in a particularly good position to get together and draw attention to the health care problems of Latinos in SWPA, but they have not taken advantage of this opportunity to date. Thus, the need for community development and organization is compelling.

## ***E. Conclusions***

### 1. The social context

Latinos in SWPA constitute several small overlapping communities. The community tends to come together because of group identification, based on language, family orientation, traditions (i.e., food and music preferences) and a need to evolve into a bigger, more cohesive community. However, there are divisions among Latinos in SWPA, and socioeconomic differences are the major source of those divisions. They are loosely organized, and many Latinos are isolated. Family income for Latinos in SWPA is low relative to their level of education.

### 2. Health and health beliefs

In general, Latinos in SWPA are physically and mentally healthy, although there is a concern for issues that influence mental health, such as isolation and domestic abuse. In general, Latinos believe in health as a holistic concept, where body and mind are one entity. Regardless of educational level, they tend to hold pluralistic beliefs about health and health care. This pluralism includes at least biomedical and humoral beliefs. Different sets of beliefs are not perceived to be contradictory by those who hold them.

### 3. Health care access

Access to health care is inequitable, as it depends on socioeconomic and cultural factors. In general, financial issues are the main barriers to potential

health care access for Latinos in SWPA. They act through income, and availability of job benefits. Cultural barriers play a lesser role in determining potential health care access. Income and education determine health insurance status. Health insurance status determines having a regular source of care. Having a source of care and sex are two factors that determine whether or not Latinos visited doctors in the past year.

In general, language and culture play a large role in realized health care for Latinos in SWPA. Financial barriers are also a major problem, but are often unseen, because Latinos resort to informal arrangements to solve their immediate problems.

Language incompatibility poses a problem for access to health services. It leads to difficulties in understanding discourse, but its importance goes beyond translation. Native Spanish speaking patients cannot communicate as easily in English as in Spanish, regardless of educational level. This difficulty is most acute when people feel sick.

Latinos prefer relationships with their providers that are personal, that is, where the provider is perceived to be warm and committed. Communication with providers is frequently perceived as inadequate, with providers failing to convey information to patients in a thorough manner, not considering their points of view, and especially, because they feel they are not treated as “human beings”.

#### 4. Alternative resources

Latinos in SWPA use community resources, primarily their ethnic networks and family relationships in a creative way to obtain health care arrangements, as well as emotional and material support. Some use formal arrangements to obtain care; others use informal arrangements. Informal arrangements are health care options outside the formal health care system, obtained through a chain of people in a network. Some resort to informal arrangements to solve insurance or financial problems of access. However, insured individuals also use these arrangements, apparently to reproduce family involvement in health care. Latinos in SWPA value family and fictive kin involvement in health and health care decision-making. Kin appear to provide

social support and improve the recovery process. People are generally satisfied with informal arrangements. However, use of informal arrangements cannot be considered a realistic solution to Latino health care access problems, as they pose risks that might lead to delayed care and/or inadequate diagnostic labels.

The absence of a cohesive community makes location of resources and concerted efforts for the common good both more difficult. Misinformation is an obstacle faced by Latinos in SWPA attempting to solve their health problems. Misinformation stems from language incompatibility and discrimination, as well as from having different sets of beliefs and cultural practices and being a non-cohesive community. Discrimination affects health care access, especially realized access. When problems to access services (i.e., finances, culture, and discrimination) are perceived to be insurmountable, people often decide to forgo or delay care. However, in many cases, this is not so much an actual decision, as it is the only choice, reflecting inequitable access to health care.

## ***F. Recommendations***

### 1. For health care

From a social justice perspective, health care providers should try to provide translators for Spanish monolingual patients, be they professional translators or community translators, through a formal agreement. For this, they may follow the Civil Rights Act of 1964 guidelines. In addition to implementing programs that address language compatibility, health care organizations should require to be training in cultural sensitivity and cultural competence for their providers. This training should include the importance of family in health and health care decision-making for Latinos, and the preference for personal relationships. Health care delivery can be modified to incorporate family involvement and communal orientation as resources for the treatment of the patient.

The first action to be taken if this research is to be useful is to inform health care providers and members of the Latino population of the problems regarding access to health care for Latinos in SWPA. If we follow the deliberative justice paradigm, the Latino population may choose to discuss this issue and

determine whether or not they will take action, such as advocating for changes in health care. Latino health professionals are in an especially good position to make the needs of this population heard by the health care community.

## 2. Future research

Several questions have been raised by this research. Many remain unanswered. Regarding health beliefs: How do Latinos integrate their biomedical, humoral and other beliefs about health and health care into a coherent whole? Is resignation among Latinos a sign of fatalism or a realistic understanding of their situation? Among which Latinos? Regarding health: Is domestic abuse a widespread problem among Latinas in the U.S.? If it is, why?

Some cultural characteristics of Latinos affecting health and health care access are not clear. What are the roles of culture and socioeconomic status in determining prevention orientation among Latinos? Do Latinos overuse emergency rooms? If they do, why? Do Latinos prefer paternalistic relationships with providers? If they do, why? Latinos have developed strategies for obtaining care in a culturally acceptable way. What is the role of women in initiating and maintaining social networks? How do Latinos make health care related decisions? Can a model be developed?

Some issues that relate to the environment, like discrimination, influence health care access. How great is this influence? To what extent do Latinos receive substandard medical care due to their ethnicity?

Most research has been undertaken from a distributive justice perspective, and some from a social justice perspective. However, the deliberative justice paradigm has been largely unstudied as a component of policy formulation and program implementation for Latinos in the U.S. Research on this point could contribute to a better understanding of the role of community involvement in its members' health care.

