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**RESPECTING AND PROVIDING: MACHISMO AND COMMUNITY
PARTICIPATION IN LOW-INCOME, URBAN QUITO COMMUNITIES**

**by
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DISSERTATION

Submitted in partial satisfaction of the requirements for the degree of

DOCTOR OF PHILOSOPHY

in

NURSING

in the

GRADUATE DIVISION

of the

UNIVERSITY OF CALIFORNIA

San Francisco



ACKNOWLEDGMENTS

To the many people in San Pablo, Cabascango, and The Support Foundation who gave their time and energy to be a part of this study,

To Cindy Bishop, Maggie Leaventry, and Betty Van Engen who assisted me with entry into their chosen communities,

To my dissertation committee at the University of California, San Francisco, for their technical assistance and theoretical wisdom,

And to my fellow students and colleagues who were a support and inspiration,

I give thanks.

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ABSTRACT

Respecting and Providing: *Machismo* and Community Participation in Low-Income, Urban Quito Communities

Donelle M. Barnes

Community participation, one component of Primary Health Care as defined by the World Health Organization, is the process by which individuals and groups exercise their right to play an active role in the development of health services. It is conditioned by the culture, society, and people who engage in participatory behaviors. Except for case studies, there has been little systematic research on community participation in actual settings and within specific cultural contexts. Using a grounded theory methodology, this study describes participation in three low-income, urban communities in Quito, Ecuador, analyzing participation as it actually occurs. Findings include a theory of respecting and providing as mutually occurring behaviors in interactions between community members and health care providers. When community members respect, support, and collaborate with health care personnel and, at the same time, as health care providers provide for, share resources with, and represent the community to other health care organizations, there is increased participation. Conversely, participation is discouraged when health care providers attempt to control the community, blame community members for their health problems, and subordinate the needs of the community for their own needs and desires. Health care providers interacting with low-income, urban communities can encourage participation by providing for community needs that are perceived by the community individually and collectively.

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CHAPTER 1

INTRODUCTION AND RESEARCH QUESTION

The World Health Organization (WHO) has proposed that community participation (CP), an important component of primary health care, is necessary to adequately address community health problems (WHO, 1991). Community participation has been defined at various levels, from individuals attending a clinic to community committees deciding health priorities (Rifkin, 1981). One assumption of the community participation (CP) concept is that both individuals and communities should be and are able to participate with Ministries of Health and WHO mandates to determine health priorities. Another assumption is that communities should and should desire to be self-determining, to practice self-care, and to use their own resources for health care.

There are both theoretical and practical limitations to current definitions and uses of the concept of community participation. Communities are expected to solve health problems, although the power to make health care decisions is held by professionals. Additionally, most communities do not have the resources necessary to solve health problems (Rice, 1988; Stone, 1992). Some theoretical literature defines what CP ought to be and case studies have been published, including some within Ecuador (PAHO, 1984). However, there is little systematic research to demonstrate how participation works across multiple communities, how health care professionals foster participation, or how participation can be measured (Rice, 1988; WHO, 1991). In addition, the oppositional concepts of professional dominance, external control and community powerlessness have

not been adequately explored (Farrant, 1991; Mburu, 1989).

Nursing research and practice literature on CP or community self-care is limited. Most nursing theory frameworks focus on individuals rather than groups, discussing client participation in terms of individual clients following nursing advice. The lack of theory to describe community structure and function limits nursing's ability to address community issues in practice and research. Nursing research is needed on community as client and participation at the group level to address this gap in nursing knowledge. This study defines the client as a community or interactive group, rather than as an individual within a community.

STUDY AIMS AND SIGNIFICANCE

The purpose of this research was to explore the process of community participation in urban, lower-class communities in Quito, Ecuador. Specifically, the study aimed to describe the participation of a community with other communities, individuals and organizations around issues of health care. Without relying too heavily on previous theory or prescriptive policy statements about what participation ought to be, I studied participation in a natural setting over time. The eventual goal was a theory of CP that explains the variety of actions and reactions of communities to health care delivery. Because the aim of the study was exploratory and theory building, a qualitative approach to data collection and analysis was utilized, specifically the grounded theory method.

This study contributes to current knowledge about communities and their

participation in health care. It adds to existing single case studies of CP knowledge of the client's view of participation and the processes and strategies of participation.

Additionally, the findings can be used to further community participation policy formation by the World Health Organization and its member countries. While community participation is currently a part of WHO/PAHO policy statements, little research has been done on how it works in natural settings, what happens when it does not work, and its limitations. Lastly, although the main intent of this study was exploration and theory building, the results will inform health care providers and administrators about CP processes, encouraging participation if desired, and understanding and accepting community non-participation rather than labeling a community non-compliant.

RESEARCH QUESTION

In an exploratory, qualitative study such as this, specific research questions emerged and were refined during the ongoing processes of data collection and analysis. The initial research question or guiding hypothesis was, "When, how, and for what reasons does a lower-class urban community with limited resources participate with health care professionals and professional organizations, public health and government officials, and other communities in the various aspects of health care delivery?" This initial research question was meant to generate interview questions and a search for patterns in the initial data while retaining the flexibility necessary to refocus the research based on concepts as they emerged. The following specific questions were helpful as a

starting point for observation and interviewing:

1. What are the patterns of participation of a lower-class, urban Ecuadorian community when participating with other communities, organizations, and individuals in health care?
2. Who in the community acts on behalf of the community and how do they demonstrate participation?
3. How does participation change over time? What are the various strategies of participation in the different stages of health care delivery -- the planning, execution and evaluation stages?
4. What are the indications and mechanisms of community dissension or refusal to participate with other communities or institutions?

ASSUMPTIONS

The following assumptions guided the study:

1. Human beings, through interactions and transactions, establish relationships with others, within dyads, families, small groups and society (Kelley & Thibaut, 1978; King, 1981; Spiegel, 1971).
2. A community is one level of small group organization and is defined as a group of individuals who share an identity, mutual influence and reciprocal interaction (Heller, 1990; Nelson, Ramsey, & Verner, 1960; PAHO, 1976).
3. A community, as one example of a social system, influences individuals' perceptions,

values, judgments and behavior. In turn, the community is influenced, changed and developed by the interaction of individuals within the group and by the group's interaction with other groups, organizations and individuals within society (Cooley, 1956; King, 1981; Neuman, 1980; Spiegel, 1971).

4. Community health nursing examines not only the health of individuals in community but also the health behaviors of the community as a group within a larger social context (Chalmers and Kristajanson, 1989; Dunn and Decker, 1990; Hamilton & Bush, 1988).
5. CP is a desirable phenomenon, from both the community's and health care professional's point of view, rather than imposed expectation from a Ministry of Health or the WHO. Participants in the second and third communities agreed that participation was desired and sought, at least to some degree.

Because the aim of this study was to observe communities as collectives rather than as individuals, Chapter Two reviews some of the available literature on definitions of community within nursing science and sociology. Chapter Two also reviews community participation literature as a theoretical basis for this research. Because this study took place outside the United States, social, cultural, and political data about the Ecuadorian context of the study is also reviewed.

Since this study aimed at describing and developing theory about community

participation, Chapter Three describes the methodology, with emphasis on the grounded theory method of data collection and analysis.

Chapter Four describes the three communities in the study, answers the four specific research questions, and discusses some general observations and conclusions about the existence of community participation in health care delivery. In particular, I discuss reasons for the lack of participation, the use of power and participation, and the role of community volunteers in participation.

Chapter Five creates a grounded theory of participation as community *machismo*, in which the community acts as female and health care professionals as male in a mutually dependent relationship. Finally, Chapter Six summarizes the description and theory of community participation in poor, urban Ecuadorian communities and suggests further research and implications for practice.

CHAPTER 2

REVIEW OF THE LITERATURE

The client focus of this study is the community as a collective, an interactive group. Because current nursing theories were largely developed with the individual as the client, I review current definitions of community within nursing, sociology, community studies, and related literature. Additionally, the theoretical focus for this study is the concept of community participation as used by the World Health Organization and CP will be reviewed based on international community health studies and related literature.

Since this research took place outside the United States, and since the political, social, and economic context of research participants influences their point of view about a problem, it is appropriate to describe the research context. A brief overview of the history, politics, social norms, and ethnic mix of the country of Ecuador is included.

DEFINITIONS OF COMMUNITY

It is no longer acceptable to assume that nursing services directed to the individual will result in improved health outcomes at the community level (Chalmers & Kristajanson, 1989). The goal of community health nursing is not only the well-being of the individual or family, but of the community as a whole (Dunn & Decker, 1990). This community as client concept differentiates community health nursing from other areas of nursing and prescribes a unique field of inquiry within nursing (Hamilton & Bush, 1988).

There is an ideological shift within community health nursing away from a belief in the individual nature of health and illness toward an acknowledgment of the collective nature of these phenomena.

If health is to be viewed collectively, and if community health nursing is to concentrate on the community as the focus of nursing intervention, the conceptualizations of community must be more fully understood and incorporated into nursing scholarship. Sociologists define community as a set of relationships among people living in an area within which most basic, daily human needs are satisfied, a focus of social life, or the common living of social beings (MacIver, 1970; Nelson, Ramsey & Verner, 1960). People come together in community when they share a common history, an identity, emotional closeness, and destiny (Heller, 1990). While traditional definitions of community focused on the geographical nature of human interaction, communities are defined increasingly by identity and influence rather than geographical location (Nelson et al., 1960). There are no precise boundaries of a community since it may be formed by the interaction of people across geographical or political lines. Particularly in urban areas, people are usually members of more than one community. Examples of communities are a neighborhood, a cultural, religious or political group, or a professional organization. All are communities with different but potentially overlapping sets of individuals.

In 1976, the Pan American Health Organization similarly defined community as:

A social group determined by geographic boundaries and/or common values and interests. Its members know and interact with each other. It functions within a particular social structure and exhibits and creates certain norms, values and social institutions. (p. 4)

Nurses who view the community as the target of practice define community as the group that individuals create, emphasizing the community as a collective (Sills & Goepfing, 1985). The essential elements of community are a sense of solidarity, significance, and security with members of the defined group (Chalmers & Kristajanson, 1989). Community, as a social entity, is more than the sum of its individual members (Stoner, Magilvy & Schultz, 1992). Community is collective action in regard to common concerns, a bond between individual members, and a type of human relationship or social interaction (McMurray, 1990). The goal of change at the community level is the common good, the well-being of the group as well as individuals within the group (Gerson, 1976; Sarason, 1974; Sills & Goepfing, 1985).

Nursing research with a community focus, community as collective action, is currently limited (Stewart, 1990). Most research within community health nursing focuses on individuals within a community who have or are at risk for disease. A community as client approach must focus on the ongoing processes within community that foster both the health of individuals and group problem solving.

For this study I chose urban communities because of the increasing number of health problems faced by growing urban populations worldwide and because urban groups are my familiar workplace. Lower-income communities were chosen because of

the greater number of health problems faced by those with limited financial resources, although it may be useful to compare one or more communities of a higher socio-economic status with those of a lower status.

The urban context for the selected communities is significant as it sets the stage for the health problems encountered and affects community participation. Cities today are characterized by demographic congestion in structurally large areas where work is related to the production of goods and services rather than the production of food (Bookchin, 1987; Weber, 1969). In other words, a city is not only a geographic and ecological unit, but an economic one as well (Park, 1969). Some of the physical and economic problems of cities, particularly for the poor, include unemployment or subemployment, substandard housing and utility services, illiteracy, a lack of child care (Scheper-Hughes, 1992), and giant, impersonal institutions (Bookchin, 1987), among others.

As well as a physical organization, a city also possesses a moral order. According to Park (1969), the physical and moral orders of a city mutually interact to mold and modify one another. According to Bookchin (1987), in the past a citizen's love of his or her city was accompanied by a loyalty to its welfare within a moral and ecological context. In contrast, cities are now defined by the expectations of individual taxpayers and consumers who demand a return on their investment. The resulting moral problems of the expanding, consumer-oriented city are anonymity, a pressure to homogenize, a sense of personal incompetence and public detachment, and a loss of identity (Bookchin, 1987). These and other factors, such as the threat of violence, rural to urban migrations

(Scheper-Hughes, 1992), delinquency, crime, corruption, and disorder (Wirth, 1969) are characteristics of the environment for urban communities.

COMMUNITY PARTICIPATION

Particularly within developing countries, including most of South America, the World Health Organization has a strong voice within health care planning and implementation. The WHO's health care policies are respected and frequently implemented because of its worldwide professional, political, and financial influence. One such policy that has been popular within the last two decades is community participation in health care. The concept of CP arose out of the International Conference on Primary Health Care in 1978 in Alma-Ata, in the former USSR, sponsored by the World Health Organization (WHO, 1978). The purpose of the conference was to set a new international agenda for health care, urging action by all governments, health and development workers, and the world community to protect and promote the health of all the world's people.

The Declaration of Alma-Ata defined primary health care to be (WHO, 1978):

essential care based on practical, scientifically sound and socially acceptable methods and technology made universally accessible to individuals and families in the community through their full participation and at a cost that the community and country can afford to maintain at every stage of their development in the spirit of self-reliance and self-determination. It forms an integral part both of the country's health system, of which it is the central function and main focus, and of the overall social and economic development of the community. It is the first level of contact of individuals, the family, and the community with the national health system,

bringing health care as close as possible to where people live and work, and constitutes the first element of a continuing health care process. (p. 16)

Of the many recommendations listed in the Alma-Ata declaration -- the role of national administrations and the comprehensiveness of primary health care, to name two -- the second recommendation referred specifically to CP. It said (WHO, 1978):

The conference recommends that governments encourage and ensure full community participation through the effective propagation of relevant information, increased literacy, and the development of the necessary institutional arrangements through which individuals, families, and communities can assume responsibility for their health and well-being. (p. 23)

There are some problems immediately evident in WHO's own definition and use of the CP concept. If communities and countries are expected to be self-determining, shouldn't they define their own participation? Since communities are mandated to assume full responsibility for their health at a cost that the community and country can afford to maintain, WHO can neither define primary health care for the community nor define how communities and governments should work together. This question becomes particularly pertinent for poor communities. A relatively rich WHO cannot define health care for poor communities and still maintain a veneer of community self-reliance. It is nearly impossible to ignore WHO, nor would it be practically or politically wise to do so. Therefore, communities and countries cannot ignore the concept of CP either. It is possible, however, to attempt a definition and understanding of CP from the community's perspective within its specific socioeconomic, cultural, and political context. It was the goal of this research to study several communities participating with government and

health care providers and institutions. This research explored how, when, and under what circumstances communities assume responsibility for their health, and if in reality they do so, as advocated by the Alma-Ata Conference.

Definitions of Community Participation

Although gaining international attention at Alma-Ata in 1978, the CP concept was not a new one. The idea of community development preceded CP and the two terms are conceptually similar. In 1956, the International Cooperation Administration defined community development as a process in which people of a community organize themselves for planning and action, define their needs, make group and individual plans to meet their needs, execute these plans with a maximum reliance upon community resources, and supplement these resources when necessary with services and materials from governmental and non-governmental agencies outside the community (Foster, 1982). Community developers believe that CP, in both community development and primary health care, is a technique to reach multiple program goals in health, education, agriculture, housing and basic services. It is significant to note that it is governments and professionals, as represented in WHO and the development literature, that are defining not only development and participation, but also the community's role in health care. The efforts of the community as a collective are meant to unite with government authority to improve conditions of communities, to integrate these communities into the life of the nation, and to enable them to contribute fully to national progress as defined by government.

There are many theoretical models of community participation and expectations

about participation are not always the same for health care planners and community members (Meleis, 1992). There are at least three definitional approaches to CP that arise from health projects: the medical approach based on health as the absence of disease, the health services approach based on health as the well-being of the individual, and the community development approach based on health as a human condition which is a result of social, economic, and political development (Rifkin, 1986). Perhaps the most significant development in the conceptual definition of CP was placing the level of decision making in the community rather than in the government. It should be noted that this is still theory and is not necessarily seen in practice.

Oakley (1989), on behalf of WHO, defined community involvement as a process by which partnership is established between the government and local communities in the planning, implementation and utilization of health activities. Oakley pointed out that, in practice, decisions were still in the hands of professionals instead of the community, using an authoritarian rather than a partnership approach. Oakley's definition concentrated on health services, did not include broader social and economic contexts, and introduced the government-community partnership at the level of planning for predetermined health goals. The community was still not given control over problem identification.

In 1991 a WHO Study Group agreed on the following definition of community involvement:

essentially a process whereby people, both individually and in groups, exercise their right to play an active and direct role in the development of appropriate health services, in ensuring the

conditions for sustained better health, and in supporting the empowerment of communities for health development. (p. 8-9)

The Study Group recognized the interchangeability of the terms involvement and participation, and stated that involvement can proceed at various levels, including contribution to predetermined programs, organization to structure programs, and the power to decide essential health needs. This definition encompassed individuals and collectives, as did Foster's model in 1982, and targeted not only health services but the broader social conditions for health. For the first time, this definition used the term empowerment in relation to participation.

Participation and Improved Health

Through its extensive experience in international development projects, the Kellogg Foundation learned that positive health outcomes for individuals were only possible when health care was requested by, led by, and owned by the community and country (DeVries & Sparks, 1989). Without community involvement in planning, health care plans usually failed due to nonacceptance by the community, and individuals were left without health resources. While the public health sector currently engages communities in prescribed disease treatment and health promotion goals (Alderslade, 1990), there is increasing realization that treatment services alone cannot resolve the problems of health in societies. A stronger, more organized community may be necessary to promote health and prevent disease through empowering individuals, reducing stress, enhancing social competence and providing support systems (Hancock, 1988).

Community participation proposes collective activity or group process that leads toward positive health outcomes at individual and group levels. Outcomes resulting from CP are increased health resources, improved planning with community knowledge of its own needs, better resource mobilization, and community member education (Rifkin, 1980). These are community outcomes that should be considered along with individual and family health outcomes. Additionally, it must be recognized that there are frequently discrepancies between how health care professionals and community members define health and health care goals (Meleis, 1992).

Two possible models of community health within nursing science are community competence (Goepfinger, Lassiter & Wilcox, 1982) and healthy cities (Flynn, Rider & Ray, 1991). A community is competent if it can interact effectively to construct and utilize structures that allow it to manage the problems of its collective life and its members to lead satisfying and productive lives. One of the eight essential conditions for community competence is participation. Flynn et al. (1991) studied six healthy Indiana cities where healthy city committees had been formed. Committees, averaging 18 members each, were comprised of members specifically recruited from pre-determined categories. Categories included business, arts, education, health department, mayor's office, media, recreation, planning and housing, transportation and others. The committee then identified health problems, the strengths of its city, and plans for change. Results were reported based on numbers of community members involved in meetings and the number of health care problems addressed. No long term results on the effectiveness of community action were reported.

Health Care Professionals and Participation

Community participation models may provide a different emphasis for nursing intervention, an emphasis on the public as well as the individual. Rifkin (1981) reviewed four approaches to how the public participates with health professionals. The first is the public health approach where the professional decides the health problem and the public follows the doctor's advice. The second is the health planning approach where professionals are team leaders and the public acts as consultants or organized committees under the supervision of the professional. Community development, the third model of participation, uses the professionals as consultants and the public defines the need for the professional. The last approach is the self-care approach, according to Rifkin, where professionals are peripheral and the public must meet the needs which the health care system is unable to meet.

There is no homogeneous view of the public's role in health. The desired health outcome is different in each of the CP models (Rifkin, 1981). Public health departments wish to eradicate disease, health planners want to expand resources and manpower, community developers wish to promote better living conditions for the entire community, and self-care groups want to meet common interests or specific needs for individual members. While many advocates of participation criticize, for example, the public health professional for being too controlling, it may be the most effective model when the goal is disease treatment or eradication. However, disease eradication is not the only goal of health professionals. Other roles for health professionals may be necessary when the health concerns have broader social and economic impact.

No nursing theorists concentrate on groups or the community, so participation for nursing is applied to individuals. Nursing education is moving toward a primary health care framework, but "nurses, like other health care professionals, may resist reallocation of power and removal of status differentials with respect to consumers of services and lay helpers" (Stewart, 1990, p.20). Recognizing that professionals in the community hold more power than do community members constrains the development of full community participation (Meleis, 1992).

The country of Colombia is attempting to change the emphasis from clinical medicine to a community orientation with a new medical school curriculum which emphasizes community medicine throughout the program (Bender, 1989). Primary health care workers are also being trained in methods relevant to village participation in planning where lack of such participation has led to weaknesses in health care delivery (Shoo, 1991). WHO believes that multi-professional education of health personnel is necessary to implement primary health care, and that community involvement must be addressed in that preparation (WHO, 1988).

Nursing as well as medicine has been mandated by member countries of WHO to take community involvement into account in health planning and care. In 1986, a WHO Study Group reported that nurses were largely trained for bedside care in hospitals and not as providers of community care. The report recommended planning the curricula of nursing programs in collaboration with community representatives and other health sectors.

Measurements of Participation

Rifkin, Muller & Bichmann (1988) devised a framework for measuring CP using five variables: degree of community involvement in leadership, organization, resource mobilization, management, and needs assessment. Each of the variables was measured on a continuum from total professional control to total community control. While this assessment did not yield an absolute index of CP, it was useful to compare two participant's views of the same community or to describe the same community over time. It is possible that Rifkin et al.'s (1988) measure of CP can provide a basis for measuring community self-care. For example, understanding the leadership and organization of a community may provide information on how that community uses power and views its own ability to create change. Likewise, a community needs assessment can provide evidence of a group's values and beliefs about health, motivations to make changes, and self-concept in relation to other communities and the national health care system which provides health care to individual community members.

ECUADOR

Ecuador, one of South America's smaller countries, is located on the continent's west coast and includes coastal, mountainous and jungle regions, along with the Galapagos Island chain. Ecuador relies on crude oil found in the jungle, and shrimp and bananas from the coast, as major commercial exports (Cockcroft, 1989). Guayaquil, Ecuador's largest city, spreads out around the tropical coastal port where primary products are exported and manufactured goods imported.

Quito is the country's second largest city and the nation's capital, with a population of about 1.5 million people (Angotti, 1995). Quito is also the world's second highest capital city at an altitude of 9,250 feet in the Andes mountains, and about five miles from the earth's equator (Cockcroft, 1989). Quito was established in 1534 and laid out around a central plaza, fronted by a Catholic church and surrounded by government offices and stores (Sargent, 1982). The city grew outward as transportation choices expanded from pedestrian and horse to railroad and bus. Current city planning problems include the lack of a public transit system, housing deficits, traffic congestion, environmental deterioration of air and water, and a rising crime rate (Sargent, 1982).

Ecuador's history is reflected in the cultural and ethnic mix that exists in the country today. The Shyris were the native ruling class before the Incas took over the region and assimilated the native Ecuadoreans around 1487 (Rossi-Osmida, 1981). The Spanish conquered the Incas in 1533, commandeered the best farmlands for their haciendas, established the colonial system of harsh rule over the indigenous peoples, and began exporting the nation's natural products to Spain (Cockcroft, 1989; Rossi-Osmida, 1981). Ecuador did not win independence from Spain until 1822. Today the population consists of approximately 48 per cent whites and mestizos, 44 per cent indigenous people groups, and 8 per cent African-Ecuadoreans from the slave trades of the early 1900's (Rossi-Osmida, 1981).

Ecuador's political system has been described as unstable, with constant tension between the military factions, middle-class socialists, and landed conservatives (Cockcroft, 1989). In recent years there has been a military uprising at Quito's

international airport and a kidnaping of the President with ransom demands by populist commandos (Cockcroft, 1989). Although the government is democratic, it operates in a very authoritarian way and does not trouble itself with too many democratic niceties (Keen & Wasserman, 1988). Political relations between the United States and Ecuador vary with the changing bent of each Ecuadorian President and elected Congress.

As with other third world countries, widespread poverty exists in Ecuador within a class system including the poor working classes and landed elite. Current capital investments favor export industries which are not closely linked to national economies, for example, oil profits which end up outside Ecuador (Angotti, 1995). As a result, an insufficient amount of capital remains in the country for housing, roads, water, and sewer systems. For example, in urban areas only 64% of the homes have adequate sanitation, and the percentage is much lower in rural areas (United Nations, 1991). A large foreign debt and a recent war with Peru (1994-1995) has further debilitated public funding.

Economically, Ecuador's inflation stands at about 60 per cent (Cockcroft, 1989). While the family pillars of economic power -- owners of plantations, banks, and foreign trade -- manage to survive the economic ups and downs of the country's exports, the lower classes bear the brunt of the changing prices in bananas and OPEC oil (Cockcroft, 1989). As a result, the lower classes are leaving the rural areas to seek work in the cities, which continue to grow rapidly (Angotti, 1989; Keen & Wasserman, 1988). In Latin America, from 1975 to 1990, 123 million people migrated to urban areas (PAHO, 1993a). Additionally, the extremes of wealth and poverty are widening and there is a decline in quality of life.

Poor populations concentrated in the larger cities suffer from high levels of malnutrition, diarrheal disease, endemic cholera, respiratory illness, malaria, tuberculosis, and complications of birth, which are mostly preventable diseases and conditions. For example, in 1992, Ecuador's cholera rate was 304 cases/100,000 population and tuberculosis incidence was 52 cases/100,000 population, although mortality rates were falling (PAHO, 1993a). As of 1990, the infant mortality rate had declined to 63 deaths per 1000 live births (United Nations, 1991). The epidemiological cycle of canine rabies remains uninterrupted in Ecuador, with a noteworthy 31% increase in cases of human rabies in 1992, mostly in Guayaquil (PAHO, 1993a). With growing urban populations and growing poverty, urban violence is increasing, most notably homicides and kidnappings for extortion.

The Ministry of Public Health admits that the high level of illness and low capacity to access services reflects the historic injustice of economic and social development in Ecuador (MSP, 1992). Current health services are insufficient to cover large sectors of the population at risk. While employment is deteriorating, both in terms of the number of jobs and real wages, there are cutbacks in public funding, notable in the quantity and quality of medical benefits under social security. Currently there is decreased spending on health care as a percentage of the gross national product, reduced delivery of services, deteriorating sanitation services, a serious hospital crisis, and a reduction in the number of beneficiaries covered by Social Security.

Some of the most commonly defined cultural characteristics of Latin America include familialism, machismo and gender roles, Catholicism, social stratification and

authoritarianism, the importance of interpersonal relations over rules and laws, and the use of time (Geyer, 1970; Harrison, 1985; Marín & Marín, 1991). Assuming that these are accurate representations of Latin American culture and, more importantly, of Ecuador, it was necessary to consider, for example, the role of social stratification and authoritarianism in examining the participation of lower-income communities with government and professionals. I found that gender roles within Ecuadorian families were also present at the level of the community as a group, and I explored *machismo* in group interaction. The authoritarianism of Ministry of Health officials and health care providers over urban communities was observed to shape community participation in ways that would not be contemplated in North America. Similarly, other cultural values of Latin America and Ecuador were considered alongside the phenomenon of participation.

Some argue that Hispanic or Latino cultural identifiers are stereotypes and oversimplifications of Latin culture. Flores Mora & Gonzalez Suarez (1990) said that problems with Harrison's (1985) and others' stereotypes are the facts that national identities are not fixed over time, that national identity is not shared equally by all socioeconomic levels and geographical areas, and that native ethnic groups' contributions to culture are omitted as are external influences. Despite these possible limitations, there is a strong history of South American relations with Spain, and many Hispanic characteristics do appear in Latin America. The generalizations about Latin American culture were not assumed to be true but were kept in mind as data collection and analysis progressed.

In summary, the definitions of community from nursing, sociology, and

community studies literature guided my definition of a community as a collective for observations and theory building. Similarly, a description of Ecuadorian society and culture guided my observations of participation within a specific sociological context and led to the utilization of the framework of *machismo* to theorize about participation.

The community participation literature served as a theoretical description of participation, and the World Health Organization's ideal of CP was compared to the reality of participation within this particular cultural, social, and political context in Latin America. It was difficult to specifically define CP since it is variously defined and approached in at least three different ways, as medical, health services, or community development models (Rifkin, 1986). It is probably best to view CP as a set of assumptions about how communities and health care systems ought to participate together in order to reach health care goals.

There are a number of other gaps in the community participation literature. Research is limited to case studies which try to demonstrate the ideal of CP, rather than observing CP in natural settings. What is needed is more systematic research describing participation in order to develop a better understanding of the linkages between models of participation and health care outcomes. Many CP studies also describe the individuals who are participating, such as individual clients or health care promoters, rather than the community as a group. Community participation studies should seek to describe group as well as individual behavior.

There are few, if any, proven links between community participation and improved health, although some have attempted to define health from the perspective of a

collective rather than an individual (Flynn, Rider & Ray, 1991; Goepfinger, Lassiter & Wilcox, 1982). Those definitions appear to be the most promising and require further study.

There is no absolute index or measurement of CP, only initial attempts to outline certain components of it (Rifkin, Muller & Bichmann, 1988). I believe that better descriptions of CP in practice may lead to better models of CP and more useful measurements.

The community participation literature is fairly clear regarding the problems of implementing CP when health care professionals feel threatened by it, dislike it, or refuse to participate. It was easy to fall into the role of critic of health care professionals in this study, and I had to guard against turning this study into a critique. While a critique may be useful, it was my desire to focus on the community and how the community views participation, and include the actions and attitudes of the professionals as a corollary to that central focus.

The next chapter describes the grounded theory methodology that I used in data collection and analysis of community and community participation.

CHAPTER 3

METHODOLOGY AND STUDY DESIGN

Since the purposes of this study were exploratory and theory building, a qualitative research design was selected to answer the research question. Grounded theory was specifically chosen for its flexibility in data collection and exploration of concepts, for its techniques of data management and analysis, and because I had adequate training in this method. Grounded theory is not the only possible qualitative method, but I considered it appropriate and adequate in this instance. I will review the grounded theory method, mentioning specific questions with regard to research participants, instruments, and analysis.

GROUNDING THEORY METHOD

Until recently, the Western scientific method had been viewed as the major and only valid way to approach knowledge and understand people (Leininger, 1985). New philosophical modes of discovering knowledge through a variety of approaches and conceptualizations of reality and truth are now being used by nurse scientists. There is a trend toward the discovery of the interrelatedness and interdependence of cultural, social and physical realities that shape the meaning of health and illness. Qualitative research methods recognize the interpretive and cognitive processes inherent in all social life, processes necessary to the understanding of health phenomena (Lowenberg, 1993).

The findings of qualitative research may provide a theoretical framework or identify variables, hypotheses, or theory to be tested in subsequent research.

Additionally, qualitative research results may challenge the status quo and identify new directions for inquiry, as well as provide rich descriptions of, for example, what it is like to be sick, suffer from cancer, or learn to breast feed a newborn (Morse, 1989). In this study, a qualitative approach has provided a rich, contextualized description of community participation which could not have been easily measured using standard quantitative approaches, even if such approaches had been developed.

Although multiple qualitative methods exist, including phenomenology, ethnography, feminist studies and others, grounded theory is currently recognized as one of the major qualitative approaches utilized by nurse researchers (Lowenberg, 1993). The goal of the grounded theory method is the development of an inductively derived theory about a phenomenon by using a systematic set of procedures, including coding, theoretical sampling, memos and diagrams, among others (Strauss, 1987; Strauss & Corbin, 1990). A basic assumption of the grounded theory method is that social phenomena are complex and take place in situational and structural contexts. The findings of a grounded theory study may vary in level of abstraction from description to theory production related to the phenomenon.

The originators of grounded theory, Glaser, Strauss, and others, were greatly influenced by the symbolic interactionists, specifically Mead, Blumer and others of the Chicago school (Chenitz & Swanson, 1986). Symbolic interactionism contends that human acts are based on the meanings that things have for them, and that those meanings are derived through social interaction. Individuals within social groups share meanings, and both meanings and the behaviors associated with them are shaped and changed over

time with ongoing interaction.

A grounded theory analysis relies on diverse materials including, but not limited to, interviews, transcripts of meetings, court proceedings, field observations, other documents like diaries and letters, questionnaires, census statistics and videotapes (Strauss, 1987).

A grounded theorist must be able to critically analyze situations, to recognize and avoid bias, to obtain valid and reliable data, and to think abstractly (Strauss & Corbin, 1990). To do this level of analysis, the researcher requires theoretical and social sensitivity, the ability to maintain analytical distance while at the same time drawing upon past experience and theoretical knowledge to interpret what is seen. Researchers must be reflexive, aware of their own assumptions, and should document their own biases.

While doing grounded theory analysis, the researcher constantly looks for the main concern or problem for the respondents, for what sums up the substance of what is going on in the data (Glaser, 1978). Without this focus, the analysis may only account for irrelevancies instead of being forced to integrate the findings around what is problematic to the respondents. Likewise, the analyst's choice of theoretical codes should be grounded in one of many useful fits.

Raising generative questions is essential to making distinctions and comparisons in the analysis and comes from examining and thinking about the data, often in conjunction with experiential data (Strauss, 1987; Strauss & Corbin, 1990). Insights, hunches and generative questions for data analysis come from the researcher's previous,

personal and professional experience with the same kind of phenomenon (Strauss, 1987).

RESEARCH PARTICIPANTS

In this study I examined community participation in health care delivery for three urban, low-income Ecuadorian communities. Communities were identified based on a shared identity as a group, usually denoted by a title or name given by the group, and some degree of interaction and organization as a group that is working with health care delivery. I chose urban communities because of the increasing number of health problems faced by growing urban populations worldwide, and because urban groups are my familiar workplace. Low-income communities were chosen because of the greater number of health problems faced by those with limited financial resources, defining low-income as a community where the majority of the people earn minimum wage or less. Ecuador, specifically the city of Quito, was the site of the research because it was my home and workplace from 1985 to 1991.

One limitation of this study was the number of communities that could be included. Since data collection of a single community took many hours for entry, observation, and interviewing multiple community members, and since I was working alone rather than with a research team, the number of communities that could be realistically included was limited.

Attention was given to the community's culture. The available communities largely consisted of Spanish mestizo Ecuadoreans, although one community included a few Quichua and African Ecuadoreans. Predominantly indigenous communities were not

included because they were not available through my contacts and because they exist primarily in rural areas. Additionally, the sample size of three communities did not allow for comparisons between mestizo and indigenous groups, although a comparison of these two major cultural groups would be interesting. Cultural comparisons of community participation awaits future studies.

From the several communities to which I was introduced, I chose three that met my criteria for being urban low-income and differing from each other in composition and health care system present in the community. Two communities were located geographically in Quito neighborhoods and the third was oriented toward a group of people sharing a specific disease but who lived in different neighborhoods. Two communities were located in densely populated sectors and one was in an urban-marginalized sector at the city's edge. Two of the communities had functioning non-governmental organizations and one was involved in the public health care system of Ecuador's Ministry of Public Health. One health care project focused on children's health care, one on adults and children, and the third on adults only.

The three communities were chosen for their variety and other communities were not chosen because of their similarity or lack of a person to facilitate my entry. For example, other possibilities included different neighborhoods served by other health clinics of the Ministry of Public Health. A shelter for abused women was considered but not pursued due to the lack of an entry person and possible problems with confidentiality. Other non-governmental health care programs were considered, but they did not significantly differ from San Pablo and the Support Foundation.

SELF-PRESENTATION

Throughout the study, I introduced myself as a licensed nurse [Licenciada], an employee at a Quito hospital, and a doctoral student at the University of California, San Francisco, U.S.A. I introduced myself in this way for two reasons: to be honest about who I was in order to encourage participants' trust and to establish my credentials for doing research (Hammersley & Atkinson, 1983). I explained that I was interested in the community and how community members work with health care delivery programs and projects. I said that I did not want to impose my definition of health or participation on them, but that I wanted to define their community and their participation by their own criteria. I stated these conditions because I wanted to study participation in a natural setting, rather than defining health or participation for the participants.

ENTRY AND RECRUITMENT

I have experience working with a non-profit hospital and with the Faculty of Nursing at the Catholic University in Quito, Ecuador. Through work contacts in community development and nursing education it was fairly easy to gain knowledge of and access to several communities. This type of access to communities, called informal sponsorship by Hammersley and Atkinson (1983), is known as "palanca" in Ecuador. *Palanca* means knowing someone who has influence with someone on the inside of a community. For example, a Peace Corps nutritionist who I met at a church in Quito was volunteering at a public health clinic. She introduced me to the clinic's staff where I

asked for and received permission to observe clinic activities and request individual interviews. This means of entry was not only the most culturally appropriate but also the most feasible. The local mail is not generally used as a means of communication in Ecuador and phone calls from strangers rarely generate acceptance. Acceptance and entry in Ecuador are most often obtained through the formation of face-to-face relationships, preferably through an introduction by a known third party.

Golde (1986) rightly comments that unmarried, childless adult women have no fully legitimate social place in most cultures, unless they are elderly and thus androgenized, making field research problematic for some unmarried women. I agree with that view in general, although I believe there are other ways to be accepted into the field even when unmarried, childless, and less than elderly, as I am. It appears that professional women can have a legitimate social place, perhaps because professionals are also androgenized. I always introduced myself as a nurse affiliated with a Quito hospital. That introduction seemed to furnish sufficient credentials to allow entry, particularly because I was studying health care delivery in the community. Additionally, the topic I was studying was not perceived to be threatening since I was not, for example, a single woman discussing child rearing or sex-related behavior; even as a professional, being unmarried would probably exclude me from studying certain sensitive topics. Nurses' work is women's work in Ecuador, so being a woman was more important to acceptance than was marital status.

Field researchers also acquire authority through association with the dominant Western culture (Warren, 1988) which was probably true in my case. I could not hide my

North Americaness because of my light skin and frequently accented Spanish. Some respondents asked me if I was Russian or Chilean, because of my accent, but I was never perceived as being Ecuadorian. Foreigners are fairly common in Quito so I was not the rare exception, but I was different. American culture is popular in Ecuador, as evidenced in the use of blue jeans, rock and roll music, and hamburgers. Being an American probably eased my access to the community, giving me some degree of authority, although it may also have prevented me from seeing or being told some things that are considered insider information. To reduce the perception that I was very different from the locals, I dressed in clothing similar to that worn by other health care providers in the community. My dress, therefore, varied within each of the three communities. In the first community I wore casual skirts and blouses, in the second I wore slacks, and in the third I wore suits or dresses, in accordance with what other nurses were wearing.

Warren (1988) also cautions about sexism in the field. Although, in the past, I have been propositioned by male Ecuadorian patients and doctors, it did not occur during field visits in this study. The majority of the interviews were with women, and the observations were all done in group situations with both men and women present. Community participation is not a particularly sexual topic. Sexism in Ecuador's health care system is certainly present, expressed in general denigration of women's knowledge, skills, and power. I tolerated the sexism that I encountered for mostly pragmatic reasons. Militant feminism is not well accepted by Ecuadorian men or women. Because I did not want to alienate any respondents in the field, I refrained from commenting on expressions of sexism that I encountered. Sexism is so pervasive in Ecuadorian culture that to

consciously oppose it would have required more energy than I had, and may have led to ending field access.

Once entry was arranged through a third party, I obtained voluntary verbal consent of the person in charge of the health care delivery in that community, and verbal consent of individual interview participants. I also requested permission from either the person in charge of the health care, or the appropriate community representative, to attend specific community meetings and for access to any documents related to the research question. Although written information forms were presented to participants, verbal consent was obtained before doing the actual interview [see Appendix A for information sheet]. One ethical risk of using *palanca* as a means of entry is the possibility that community members may feel coerced into granting an interview through the introduction of the third party. I was aware of this possibility and avoided pursuing interviews or contacts with community members who appeared reluctant or unwilling to talk with me.

Leaving the field happened gradually in each community. As I concluded specific interviews and general observations, I thanked participants for their time, indicating when I would return. Once I felt that I had sufficient data from one community and was ready to move on to another, I informed the health care provider in charge of the clinic or project that I would be visiting less frequently. I continued occasional visits in the first two communities while continuing data collection in the third, thereby gradually separating from the people at each site while never completely severing the relationship. The first community was most notable in this instance, because the field basically left me

before I was ready to leave the field. The children's tutoring and health program in the first community closed at the end of the school year, and the community members involved in the project dispersed. This event also ended my data collection there. Similarly, in the second community, data collection was temporarily halted when the health care providers of the Ministry of Public Health went on strike, closing the clinic and halting community meetings around health care for several months. Fortunately, by that time, I felt I had adequate data for analysis from that community. Health care within the third community was ongoing throughout the study.

DATA COLLECTION PROCEDURES

Once a community was identified and permission obtained, I entered each community with my contact person. As I drove to each community for the first time I observed the area of the city where the community was located, its people, housing, businesses, etc. I tried to get a feel for each community as a social, economic, and psychological group. My initial observations at each site were of the ongoing health care being delivered and of the people involved in the health care, both professionals and community volunteers. Once I had observed professionals and volunteers at work, I then approached them individually for interviews. Interviews were later conducted at a time and place convenient to the interviewee. The following table summarizes the type and amount of formal data collected in each community. It does not include the many hours needed to establish contact and entry, gain an overview of the community, and establish personal relationships with key people in each setting.

Community	Observations	Interviews	Other Documents
San Pablo	Children's program, elementary school, school playground, church steps, home visit, program for parents, staff meetings. Total: 24 hours	Director, nurse, social worker, school teachers, mothers, community volunteer/cook. Total: 10 interviews	Newspaper articles on elementary education in Quito, photos of the children's program on walls of church. Total: 12 items
Cabascango	Clinic waiting room, clinic garden, nurses' vaccination room, clinic pharmacy, physician's exam room, home visit, women's club meeting, comm. representatives' meeting. Total: 30 hours	Medical director, nurses, community volunteers, Peace Corps volunteers, community organizer, patients. Total: 9 interviews	Newspaper articles about the Public Health Care system, posters and articles on clinic walls. Total: 10 items
Support Foundation	Waiting room and secretary's office, Board meeting. Total: 8 hours	Foundation president, board member, nurse, community volunteers, AIDS patients, patients' family members. Total: 8 interviews	Newspaper articles on AIDS in Ecuador, public education pamphlets on AIDS. Total: 15 items

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San Pablo. The children's tutoring program was offered two days a week in a local church, which lead to observations and interviews of volunteer teachers and other community members at the church. Each time I visited the tutoring program I sat or stood with the other volunteer teachers to observe the children at play, study, and eating their noon meal. The children assumed that I was another adult volunteer and they treated me the same way they treated the other adults. I was asked to help children with school work, sit next to them, pass out food at lunch, and to participate in other regular program activities. I participated in the regular activities in order to observe first hand what kind of health care was being offered and, more importantly, how school teachers, health care professionals, and community volunteers worked together in the program. Additionally, I did not want to alienate program volunteers by refusing to participate to reduce my impact for the sake of "science" or non-participant observation. Later, in a hospital office, I interviewed the program director and other program and community volunteers who worked regularly in the health care program and could tell me about participation.

Since the children in the tutoring program were recruited from the local elementary school, on several occasions I sat outside the school and observed children coming to school, at play in the playground, and teachers talking among themselves and with mothers. I later interviewed two teachers who were familiar with the tutoring program at the church and, therefore, could give me knowledgeable information about the program. I did not interview the teachers who were newer to the school and who stated they didn't know about the program. Local newspaper articles outlined current

limitations with funding, resources, class size, and other problems with elementary education in Ecuador. In all cases, I sought to observe interactions between community members and health care providers and interviews with key community and health care representatives who had knowledge of the health care.

One of my observations of the total program and its participants occurred at the end of the school year in 1995, when I observed a closing program put on for the benefit of the parents and school teachers. Teachers and parents attended in order to watch the children sing songs and deliver skits they had learned and practiced during the year. While waiting for the program to begin, I was able to chat with several mothers in the audience.

Cabascango. I repeatedly visited the public health care clinic and spent a number of hours seated in the patient waiting area. I was able to observe patients coming and going and some of their contacts with clinic staff. From there I moved to other areas of the clinic, sitting in the vaccination room talking with nurses who were giving vaccines, walking through the nurses' room where vital signs were taken and charts reviewed, and chatting with physicians in their examination rooms. I spent a few minutes each day with the Peace Corps volunteer in the clinic's garden, where community members would pass by and talk with her about what she was growing and why. I accompanied one clinic staff person on a home visit to a mother whose child needed corrective facial surgery. In order to observe the community as a group in interaction with health care professionals, I attended two community meetings, one a monthly meeting between community representatives and clinic professionals and the other a women's club meeting. Unlike

the children's tutoring program, I did not actively participate in health care delivery at the clinic, attempting to be more of an impartial observer rather than a participant. At one point the head nurse asked me if I would be willing to help her by teaching some health classes at the clinic and, in the name of camaraderie and reciprocity, I agreed. I was worried that her expectations might occupy too much of my time, so I was relieved when she never followed up on her suggestion with any specific requests. I never mentioned the issue again and it was dropped. I preferred to be an observer rather than a participant in order to maintain some degree of objectivity and distance from the day-to-day clinic events, and in order to have time to observe and write up notes.

I interviewed members of the community and health care staff who could tell me something about the interactions between community members and health care providers. These interviews took place in the clinic when business was slow and the interviewee had time to talk with me. In some cases, interviews were not pursued with patients or other community members who did not indicate a knowledge of participation. Other interviews were pursued with individuals who had been named as community representatives in previous interviews. I interviewed one community representative in his home.

At the time of the study, some newspaper articles were discussing the Public Health Care system, its limitations and current problems. A November 6, 1995, article in *El Comercio* stated that the 1996 budget proposed by the Ministry of Public Health was 800 million sucres [approximately \$ 270,000 USD], and the Congress had cut the budget by 300 million sucres [approximately \$ 100,000 USD]. Fiscal limitations is one of the

gravest problems for public health care; 60% of the Ecuadorian population receives only public health care attention.

The Support Foundation. The third community had an office in the center of Quito. I toured the office and spoke with the volunteer secretary. However, the foundation itself did not offer regular health care to its members, so there was no ongoing health care to observe. Based on my visit to the foundation office and my contact persons' knowledge of the foundation, I personally contacted and interviewed the foundation's president, health care personnel, patients, and patients' family members who were involved in the foundation. At this point in data collection I was looking for validation of codes and ideas that had emerged from the data in the other communities. For this reason, the interviews were more specific to the codes that I was developing rather than being broad and exploratory. I was able to attend one Board meeting of the Support Foundation as a member of the audience. This provided some insight into the opinions and interaction of the Board members. I considered attending meetings of the AIDS patients support group but, since support group meetings are considered very sensitive due to the stigma of AIDS, I did not think it would be appropriate to observe those meetings. However, I did observe an AIDS clinic in a local hospital in conjunction with an interview of a nurse who provides AIDS care. Another beneficial source of data were a number of AIDS pamphlets directed at educating people in Quito about HIV, preventing AIDS transmission, and AIDS treatment. Fortuitously, the Support Foundation and a number of volunteers who had lost friends to AIDS sponsored a week of AIDS awareness in Quito during my data collection. I attended a coffee house and an

art exhibit where AIDS awareness information was given out.

Data collection lasted from mid-March 1995 to mid-March 1996. However, circumstances beyond my control hampered data collection. The first was my own illness that finally resulted in major surgery in November, 1995, causing a two months absence from the field. By then I had for the most part finished data collection in the second community and was just beginning data collection in the third. A second circumstance hampered my freedom of movement in the field. A North American missionary in Quito was kidnaped in mid-December 1995, with a ransom demand of \$500,000. Although the missionary was successfully recovered after two weeks, three kidnappers were shot and killed by police during his rescue. This led the U.S. Embassy to issue a warning to all North Americans on January 4, 1996. We were instructed in techniques to avoid possible kidnapping situations, which definitely made me think twice about traveling alone around the city, particularly at night. Fortunately, by that time, I was involved in data collection in my third community which required less traveling. I refrained from traveling at night to any community meetings because of personal safety concerns.

Role issues. Other than in the visits to the tutoring program where I participated in ongoing activities, when attending and observing organizational meetings I attempted to remain an observer rather than a participant. I wanted to concentrate on observation and data recording rather than become involved in program planning, politics, and personalities. I was aware that participation may have been expected by those present, but I was not asked or expected to participate in any community meeting. My presence alone may have altered the interactions that I observed and any participation, while not

destroying the data, may have altered it as well. My presence as another health care professional may have inhibited community members' participation. For example, in a meeting of the AIDS foundation, my presence may have prevented foundation members from speaking as freely as they might have, or may have caused them to modify their comments to appear more politically appropriate. One AIDS patient and foundation member privately told me that other community members have cautioned her about speaking critically about the Ministry of Public Health because The Foundation may have to work with the Ministry at some time in the future. Similarly, comments may have been altered to appear politically courteous or correct in my presence. There is no way of knowing what the respondents might have said had I not been present. On the other hand, those present at community meetings seemed to quickly forget my presence and concentrate on the agenda at hand.

Interviews, taping and transcription. In each interview, I loosely followed an interview guide (see Appendix B). As codes and categories emerged from early interviews, theoretically driven questions were added to or substituted for questions in the interview guide. For example, when in the first community I observed that all community volunteers were women, I included questions and analysis about the differences between men and women who participate, which men participate, what motivates women who participate, etc. I recorded interviews with a portable tape recorder when agreed to by the interviewees. Only two interviewees declined to be tape recorded, although they were willing to be interviewed.

I recorded group meetings using written notes, feeling that a tape recorder would

be intrusive, and that it would be very difficult to obtain informed consent from each individual present. Although I received permission to attend meetings from the professional and community representatives involved in each meeting, all meetings were actually public meetings.

I transcribed taped interviews and transferred written notes and documents to a computer file using WordPerfect software, and then reformatted all data with *The Ethnograph* software to numbered hard copies. All tapes, transcribed interviews, meeting notes, memos, and written documents were kept in my apartment, where I was the only one with access to the data. Transcribed interviews and other data were kept on the computer hard drive under my personal password.

ETHICAL CONSIDERATIONS

Neither interviews nor observations were anticipated to cause physical or emotional harm to participants since the topic of community participation was not particularly personal nor value-laden. This appeared to be the case. No interviewee nor other community member mentioned any adverse reactions or consequences to being in the study. I recognized that the topic could have posed a political threat to poor communities and community members, government officials, health professionals, and others, so this potential threat was taken into account when requesting interviews. Additionally, the time needed for an interview could have posed a personal burden to participants, so the interviews took place at their convenience and were terminated when they indicated that they needed to return to work. Attendance at a community meeting

could have been inhibiting to participants and prevented an otherwise usual discourse, so I requested that the health care professionals inform me if they thought I was interfering. I was assured that my attendance was no problem to them, and I was never asked to leave a meeting.

I sought to minimize the potential risks by maintaining strict confidentiality with regard to the interviewee's identity and responses, by reminding participants that their participation was voluntary and could be terminated at any time, by being sensitive to group process in a meeting. I reimbursed individual interviewees with approximately \$3.00 (USD) in Ecuadorian sucres, depending on the monthly exchange rate. To provide a context, as a nursing professor I was paid \$1.42 per hour at the Catholic University in Quito.

ANALYSIS

In a grounded theory study, analysis begins with the first interview or community observation and continues throughout data collection (Strauss & Corbin, 1990).

Language

I recorded and coded each piece of data in the language in which it was created. Interviews were conducted in English with North Americans and in Spanish with Ecuadorians. Although all health care was provided in Spanish I recorded my observations in English. I attempted to record some observations in Spanish but found it too cumbersome and inaccurate, since Spanish is not my first language. Therefore, recorded observations have already passed through one level of analysis, recording

actions, words, facial expressions, and body posture in my language rather than the language of the respondents, before coding was started.

Coding

Codes were first created in Spanish, until the level of analysis became more abstract, when I switched to English, largely because the dissertation would be written in English. For example, some of the initial codes were *comunidad*, indicating when the community as a group participated in health care, *cliente*, representing individual client participation, and *mujer*, when specific differences were observed between men and women participating in health care. The *comunidad* code was later refined and redefined as *respetando*, *apoyando*, and *colaborando*, which were directly translated as respecting, supporting, and collaborating respectively. Codes were entered into the computer files using *The Ethnograph* software, and printed out for further analysis.

Generative questions were raised around the codes that emerged in the data and pursued with subsequent interviews and observed meetings (Strauss, 1987; Strauss & Corbin, 1990). For example, early in the data collection, I identified differences between female and male community volunteers. I questioned whether or not participation was a gender specific concept, and whether gender differences in community participation were more related to power differences between men and women or to differences between community participants and health care professionals. These comparisons led me to search sociological and health care literature around gender roles in Latin America, and the use of power in social relations in Ecuador. Constant comparisons were then made between individual male and female interviews, documents about power and gender, and

between male and female participation in each of the three communities, seeking dimensions, conditions, antecedents, contingencies, and attributes of gender and power. Theoretical sampling also took place where appropriate, seeking out specific people, documents or meetings that yielded additional data around gender and power relationships in participation.

After the first few codes had been defined and explored, memos and diagrams were started that illustrated what seemed to be happening in the data from the participant's perspective (Strauss, 1987). My first diagram in the first community compared community and professional women with community and professional men along the categories of organizational hierarchy, use of authority, motivation to participate, organizational titles, and communication styles. I was then able to memo each category, looking for further ideas for interviews and comparisons. Memos provided a type of journaling of my progress through the data and explored deeper levels of abstraction for what was present in the data and for how specific codes could be related to each other. For example, in the second community I began comparing participation between the community and the health care professionals, and wrote the following memo:

Why do doctors, nurses and teachers participate? One teacher mentioned the vocation she felt, so they may feel some intangible motivation or reward, but they are also paid, given a position of power, and a job description. For services rendered they receive a salary, which allows them to live comfortably. Community volunteers are not paid, but expected to give their time and money to see a health care project succeed. In C's project the family pays money for each child, mothers bring the children, the church gives the room, all in exchange for more intangible rewards; the children will

be educated, children will be healthier, satisfaction of being involved in their community. Few get financial reimbursement. They are expected to work for the good of the children, for the good of others, for the common good. One exception might be the cook in San Pablo, who was paid a stipend to cook lunch. Does volunteerism work? Is it rewarding enough? Why do professionals get tangible rewards for their participation but the community receives largely intangibles for theirs??

Memos and diagrams were amplified, refined, reworked, linked, and discarded as data analysis continued.

Also relevant to the analysis process was the situational and structural context in which the data were created (Strauss, 1987). I sought information and recorded my ideas on Ecuadorian culture, its health care system, government involvement in communities and in health, issues of poverty, professional organizations, and other pertinent contextual information. The context of the data was considered throughout the analysis of individual interviews and observations.

Data collection and analysis continued in each community until I was satisfied that I had a general knowledge of what was happening in health care delivery in the community, and until I had some explanation of what was happening around community participation processes. Once a particular code was sufficiently saturated, I gave attention to other codes and categories until I completed an overall analysis.

Use of Literature

One step in the analysis process is to consult literature on the codes that are emerging from the data. I was greatly frustrated in my attempts to consult the literature at

the University library. I had to present two forms of identification at the library desk, along with the reference number of the book or thesis that I wished to see. I then waited about 10 minutes while one of the library employees searched for the book on the shelves. I had to use the book in the library and then return it before requesting another. No one is allowed access to the book shelves except employees, so browsing is not possible. Also, the card catalogue is not on computer so no organized electronic search was possible. All references are on cards in standing card catalogues by subject. This proved to be so frustrating and time consuming that I soon stopped attempting to find literature in the Quito library. Instead, I referenced Latin American literature through the University of California, San Francisco. This is another limitation in the analysis step of the study, referencing Ecuadorian literature may have been more specific to my study in the Ecuadorian context.

RIGOR AND ADEQUACY IN THE GROUNDED THEORY METHOD

Although internal and external validity, reliability, and objectivity are measures of rigor in the positivistic paradigm, naturalistic or qualitative research has its own parallel measures of method adequacy (Kirk & Miller, 1986). Guba & Lincoln's (1989) criteria for judging the adequacy of qualitative research are credibility, applicability or fittingness, and audibility, and these criteria are useful for qualitative nursing research as well (Sandelowski, 1986).

Credibility and Fittingness

As I went through the analysis process I tested the credibility and fittingness of

my findings by informally presenting codes and ideas to other interviewees, to community members, and to fellow professionals, seeking their feedback concerning the fit of my analytical explanation to their daily experience. For example, after analyzing differences between community members and health care professionals regarding their personal motivation to participate, I began asking interviewees what motivated them to participate and whether or not they were paid to participate. Also, when adding the theoretical construct of *machismo* to my analysis, I began asking community members and nurses whether using the concept of male *machismo* to describe the actions of health care professionals made sense to them. When I received positive affirmation, I continued to explore the idea through questions about *machismo*. This feedback continued throughout the analysis process, from the initial to final stages. Categories and explanations of the data that were meaningful to others were retained and expanded, while others were abandoned. For example, the code "communication styles," which I had identified in initial interviews, was abandoned after community members indicated that it was not important to them.

Adequacy

There are several specific threats to the adequacy of the data and credibility of findings when studying Latin American respondents. First of all, acquiescence or "yea-saying" is frequent among Spanish speakers, particularly among less educated respondents (Marín & Marín, 1991). Latinos are more likely to agree with a statement or to answer "yes" to a question than non-Latino whites, even if they do not actually agree. Acquiescence among less educated respondents is most probably due to the general

socioeconomic powerlessness that they experience in daily life, which also presents itself in research responses. This tendency may be particularly problematic in quantitative research when working with response sets, but less a problem in a qualitative interview because the context provides clues to what may be going on in reality, and allows respondents to voice their own ideas or concerns in a non-structured interaction.

However, I was aware, when presenting my codes and categories to research respondents for their affirmation, that they readily agreed to almost any explanation that I suggested for what was happening in the data. While hearing this was initially pleasant, it did not assist me in my goal of rejecting my spurious conclusions or explanations. I had greater success with better educated contemporaries in nursing and sociology, who appeared less likely to acquiesce to my explanations of the data and more likely to disagree with me.

For example, one nurse questioned whether or not *machismo* was the best theoretical model for what was happening in the data, or whether I could use the model of the *patron* system. I then reviewed and thought through the *patronal* model, but ended up keeping *machismo* as a construct, since I thought that it explained more of what was happening in participation and dealt directly with the male/female roles within the Ecuadorian cultural context.

Another threat to adequacy is the tendency among Latinos to give socially desirable responses when participating in research, and to avoid speaking about less desirable attitudes or behaviors, independent of the question asked or of their actual experiences (Marín & Marín, 1991). This may be a result of cultural values of politeness and respect which discourage criticism, confrontation, and assertiveness. During initial

data collection, when I asked about participation, respondents seemed to share my assumption that participation was socially desirable. It wasn't until I was collecting data in the second community that I questioned that assumption. I questioned further respondents about participation being truly desired by community members versus being imposed by health care providers, but all respondents affirmed that participation was good. Additionally, my observations made it clear that community members were participating by choice and some had stopped participating when they chose. I was never fully convinced that poor communities desired participation, or if they were telling me what they thought I wanted to hear. I found no way to finally resolve this conflict, although I continued to question the assumption that participation was a natural versus a coerced process in community health care.

A final threat to adequacy is the level of self-disclosure that Latino respondents are willing to provide a stranger. In general, Latinos self-disclose less than do non-Latinos, possibly because of the social norms of face-saving and social desirability (Marín & Marín, 1991). This is a methodological problem that is difficult to predict, although efforts to engender a sense of trust between researcher and respondents may enhance self-disclosure. During data collection, I spent several hours observing and meeting people at each health care site in each of the three communities before beginning interviews. While I was still an outsider to the community I was less of a stranger and, therefore, less inhibiting to self-disclosure.

Auditability

I presented my explanation of community participation to other nurses in Quito,

asking if my ideas made sense. I also presented emerging ideas with supporting description to my research sponsor, requesting feedback regarding the clarity of my presentation. This required translation of both codes and supporting portions of the data into English. Auditability is also crucial in the final reporting of the data, as the documentation of my decision trail should be clear in the results section (Kirk & Miller, 1986).

Strauss and Corbin (1990) judge the results of a grounded theory study by determining if concepts have been generated, if concepts are systematically related, if the results have explanatory power, if the results show variation and process, and if the findings seem theoretically significant. I believe that I have generated concepts in this research that do not currently appear in community health nursing literature, and that I have related concepts to each other within a theoretical model of *machismo*. Further, I believe that the results have explanatory power for urban, low-income Latin American communities who participate with health care delivery. Through the feedback of community members and other professionals in Quito, the significance of the findings were confirmed.

In Chapter Four, before answering the research questions, I begin by describing the three communities as collective groups and the health care delivery that was ongoing within each community. With this description as a contextual background, I will then address the four specific research questions and include a general discussion of participation within these low-income urban communities.

CHAPTER 4

THREE LOW-INCOME URBAN COMMUNITIES

The first community in which I observed and interviewed participants was in the north of Quito, a community I call San Pablo. (All community and person names have been given pseudonyms for anonymity.) San Pablo is a busy neighborhood of poor working-class people. The health care program that I observed was a children's tutoring and health program organized jointly by a local church and a Quito mission hospital. The program's aim was to keep first and second grade children in school, so that they might finish their primary education with the hope of a better financial future.

The second community was geographically located in the far south of Quito, a community I call Cabascango, a quieter urban community on the city's edge. In Cabascango, I observed the local health sub-center of the Ministry of Public Health of Ecuador.

The third community I chose for its identification with a health problem that the group had in common -- AIDS. Although the community members lived and worked in various neighborhoods in Quito, they came together because of the social stigma of AIDS and the lack of health care available for AIDS patients. Together they formed an AIDS foundation which became for them a community.

THE COMMUNITY OF SAN PABLO: A TUTORING PROGRAM

Located in the north-east sector of Quito, San Pablo is a densely populated

neighborhood of poorer people. The main streets leading into the neighborhood are asphalt paved, but the side streets or residential areas are laid with cement blocks, cobblestones, or remain dirt roads. The hilly area occupied by the neighborhood has been filled with cement block buildings of two to three stories, both businesses and homes, painted white, beige or another light pastel color. Many roofs are gray corrugated fiberglass, some have traditional red tile roofs.

Scattered throughout the neighborhood are partially constructed buildings, cement block shells without roofs or windows. Some families live on the first or second floor of a building, with unfinished upper floors, leaving the impression of the building being unsettled or incomplete. In front of the unfinished buildings a pile of dirt frequently sits waiting for someone to finish the job and clear away the evidence.

During daylight hours the busy thoroughfare into San Pablo is crowded with cars, buses, delivery trucks and pedestrians -- men, women and children. There is one traffic light half-way down the main street controlling the slow progression of traffic. The three-foot wide center divider, dividing the two lanes of traffic, is piled with garbage left for the trucks that come through three times a week. Stray dogs dig among the garbage for food, while women and children sort through the refuse looking for salable or recyclable material. Along the main street are mostly businesses: markets, produce stores, hardware stores, auto repair yards, restaurants, and professional offices. Pedestrians dart in and out among the vehicles, while buses stop wherever they choose to take on or let off passengers. Frequently the air is pierced by the angry cry of a car horn, telling pedestrians to get out of the way, or prompting a bus to move on.

Electric lines are strung down the streets, along with telephone lines. There are manhole covers for the sewer lines on the main streets and some side streets. The residents report that water pressure is very poor in the neighborhood, and there are hours of the day when no water at all comes out of the pipes. Most families have water tanks or containers, usually of plastic, that are kept full for the times when there is no city water.

The culture of San Pablo is largely a culture of urban poverty. Although there are families of Otavalens, African Ecuadoreans, and Spanish mestizos living in San Pablo, their individual differences are lost in the unifying factors of urban growth, subemployment, poverty, government-controlled utilities and services, and urban family systems. San Pablo, like many new urban areas of Quito, was originally settled by squatters. According to Ecuadorian law, if a group of people can demonstrate that they have continually resided in a geographical location for more than a year, they have the right to legally claim the land, even if originally owned by someone else. Once enough residents move into a previously unsettled area they can begin requesting city water, sewage, electricity, and phones. The whole settlement process usually takes five to ten years.

San Pablo is a community of poorer residents who were drawn to the city from rural areas and smaller Ecuadorian towns. As with most migrations, the previously rural labor force seeks more employment, better housing, and more favorable living conditions in the city (Angotti, 1995). Unfortunately, while the city attracts rural people, it cannot adequately absorb them into its economic base. Jobs generally available include factory work, manual labor paid by the day, maids of rich households in other parts of Quito,

laundry services from their homes, and sales of small products on the streets, called *vendedores ambulantes*. Some residents have steady employment, but many jobs are paid by the day, can be canceled at any time, or are dependent on their own initiative in finding buyers for products. It is common for both parents in a family to work from sunup until sundown, about 12 hours a day, to make enough money to survive.

Due to the rural to urban migration, many families now live without the extended family members who used to be a part of family life. Rather than living close to extended family households, what Keefe (1980) called the localized kin group, a typical family in San Pablo contains only a nuclear family, or a single parent with children. There are no statistics available for Ecuador on how many households are headed by a woman alone (United Nations, 1991). Some children no longer live with their biological parents, who have left the children to seek employment elsewhere, but live with grandparents, uncles, and aunts in the city. Because extended family members no longer live nearby, older children generally care for younger children at home while both parents work. This results in many school age children leaving school before the sixth grade.

Another reason for children dropping out of school is their enlistment into the labor ranks to help provide for the family. Children from five to fifteen years of age are a common sight on the streets of Quito, selling newspapers, candy, gum, bags of fruit, and other small products. Male children frequent airports, central plazas, and some businesses as shoe shiners. Female children may join their mothers selling produce, washing clothes, or working in a shop or home.

A typical community home has the address painted in white paint on a black

metal gate set in an unpainted cement block wall about six feet high. Entering the gate there is a large open dirt area, occupied by clothes lines, a couple of dogs, four or five chickens, several adults and children. At the back of the lot there may be a wooden shack or two, painted or left a natural plywood brown. The shacks are usually a single room, containing beds, dressers, tables, with other personal items stored in cardboard boxes under the beds and tables. Frequently, portable gas tanks are attached to a cooking stove seated on a table. At the front of the lot there is usually a cement block latrine and a cement sink with piped water, and there are usually electric lines strung into the property for lights and electric appliances. Rent for such a property runs around S/.80.000 (eighty thousand sucres or \$31.40 USD) a month and renters may be disgusted that they have to pay that much for such poor housing. Electricity and water cost about S/.10.000 (ten thousand sucres or \$4.00 USD) per month.

The Elementary School

About six blocks off the main road into San Pablo is the local public elementary school. The school is completely surrounded with metal cyclone fencing, with a gate at the driveway entrance. Immediately inside the gate is a play area, partially cemented and partially dirt. Behind the play area are three, one-story cement block buildings, arranged in a U-shape, with corrugated fiberglass roofs and windows along the two side walls. The school accommodates kindergarten children in the morning hours, and first and second grade children in the afternoons. The children wear navy blue uniforms with light blue trim, regulation black or tennis shoes. The children's family pays about S/.59,000 (fifty-nine thousand sucres or \$23.20 USD) per child per year for school registration,

uniforms, and paper supplies. Some families remove their children from school because they cannot pay the required fees. The classrooms have no heat source. On one cloudy day of observation, wind and rain came into the school yard. I was shivering with cold while the teacher and health care program director talked about each child's progression through this year's material.

A Children's Tutoring Program: An N.G.O.

The tutoring program that I observed in San Pablo is an example of a non-governmental organization (NGO). Although there are many definitions of NGOs, they are literally any organization that is not part of the government structure, and therefore of the State. More specifically, an NGO is a civil organization, privately developed, without the intention of making a profit, whose work is oriented to serve the social sectors or some distinct population group (PAHO, 1993b). Common examples of NGOs are institutions dedicated to direct social action (food, health, culture, or communication), to academic work (teaching, research), or to a combination of action and research. In Ecuador, 62.3% of all NGOs are registered in Quito.

There are 160 registered NGOs in the health care arena in Ecuador, 82% of national origin, and 18% from foreign organizations (PAHO, 1993b). The health NGOs are involved in acute health care activities (43.8%), prevention of disease (13.7%), rehabilitation (13.0%), health promotion (6.2%), and others (23.3%). The benefits of NGOs are largely to individuals (63.7%), with few activities going on at the community or collective level (2.7%) (PAHO, 1993b). In Ecuador, the Ministry of Social Welfare legalizes social NGOs, while the Ministry of Public Health legalizes the health NGOs,

including foundations, societies, associations, federations, missions, corporations, and centers. The majority of the health NGOs state that they have no relationship (45.9%) or only occasional contact (28.8%) with the Ministry of Public Health, indicating a lack of coordination of the NGOs with the Public Health sector, and the NGOs with each other. Therefore, there is no organized effort, public or private, to coordinate health care coverage for all of Ecuador. Many NGO programs are very localized with little overall social impact. It is estimated that NGOs services cover only 5% of the Ecuadorian population (PAHO, 1993b).

The Pan American Health Organization recognizes that NGOs are indispensable for amplifying the capacity to offer social and health services. This reliance on NGOs is partly due to the crisis within the State in its ability to manage health care resources and meet health care demands. Some argue that what is needed are not more private voluntary organizations, but a greater effort by the State to serve the population's health needs. Nevertheless, the NGOs have the ability to serve some of the people, and have the potential to specifically contribute in areas of health research and training.

The tutoring and health program started in San Pablo in 1989, when a local church pastor observed that many of the elementary school children were not successful in school. He asked church volunteers and a nurse from a Christian mission hospital in Quito to start a tutoring and health program for the children. The first year the adult volunteers met once a week with a group of children, tutoring them in their school work. In the second year the program organized a bit more, asking the local elementary school for referrals of students unable to pass the first or second grade. The staff met with the

students two mornings a week during the school year, and addressed such health concerns as psychological evaluations, vision testing, nutrition, and general health teaching. The program now runs under the management of the mission hospital, and has been approved by Ecuador's Ministry of Education as a *programa de recuperación* (recovery project).

The main goal of the program, according to the director, is to help the children gain confidence in their school work, and to motivate them to continue in school. The program's volunteers accomplish their goals by demonstrating love, acceptance and encouragement to the children, goals consistent with a mother's role in Ecuadorian society. The secondary goal is to teach school subjects, such as math, reading and writing. Most of the students are at least a year behind their age group in advancement through elementary school. The program also seeks to address health concerns by feeding the children lunch each day, teaching oral and general hygiene, and organizing and funding health screening when needed. All the children have received a psychological evaluation this year in an effort to identify social, emotional and behavior problems associated with their learning problems in school.

The program director is a female American nurse from the mission hospital who is responsible for finding funding, organizing, and administering the program. She also works directly with the children during the twice weekly sessions, along with several other female volunteers. The director reports to an administrator at the mission hospital, although their contacts are infrequent and the perceived amount of support from administration is very weak. She has lived and worked in Ecuador for 10 years, and is

paid a salary by the hospital. In Ecuador, she has two years hospital nursing experience, and eight years experience working in community development projects. She personally lived in San Pablo for one year, but moved out due to lack of services, such as running water and distance from other expatriates. It was through my personal friendship with and knowledge of this nurse that I was introduced to San Pablo, both the larger community and the tutoring program.

There are seven other program volunteers, four Ecuadorian and three American women. Some volunteer both days each week, Monday and Wednesday, and others only come for one day. They do not receive a salary for their work. The women are volunteers to this program and are not paid a salary, and they all have some form of income. Two women are married and supported by their husband's salaries. Another married woman is partially supported by her husband and works part time, volunteering two mornings a week to this program. One woman is a social worker at the same hospital that employs the program director and is given permission to work one morning a week in San Pablo. All the women work together cooperatively, seeking guidance and decisions from the program director. I observed no jealousy, competition nor arguing among them.

The program's activities were initially funded by the director's personal money, and later funded by donations from individuals and charitable groups, principally churches, in the United States. Each child is expected to pay S/. 200 (two hundred sucres or \$0.08 USD) per day that he or she attends the morning's program. One mother said that the cost was nothing, and she was very thankful that she could send her daughter.

There is a waiting list of children who want to be included in the program, the number of children being limited by the number of volunteers available to teach them. Children are allowed to continue in the program for two years. After that there is little else that the program can do for the children, according to the director. Currently enrolled in the program are three (3) Quichua, three (3) African Ecuadorian, and 12 Spanish mestizo children. There are about equal numbers of boys and girls in the program.

About four blocks off the main street through San Pablo and a half block to the right, down a single lane side street, is the evangelical church. This is the location of the children's tutoring program. The building is two stories, painted beige, with a staircase rising up the outside of the building from the street level to the second story. Standing in front of the building is a high cement block wall, painted the same color as the building, with a black, locked metal door in its center. The building's paint is fresh and clean, the building clearly labeled, and its appearance shows a sense of pride and care.

Entering the metal door, the first floor or street level consists of a bathroom with cold running water, and two or three small meeting rooms. The second floor is entirely taken up with a larger meeting room, a sort of church sanctuary, with long brown benches, a black piano, a plywood locked cabinet in one corner, and a very small podium with a brown lectern on it. The floor is gray cement, the walls are painted white, and there are windows on the two side walls of the room. A bulletin board on the back wall of the room displays a list of the church's activities and several photographs of the children in the tutoring program. The room is cool, although the sun is shining outside,

and feels gray and drab as though it lacks color and life.

Each Monday and Wednesday morning, when the program director and volunteers arrive around 9:00 a.m., several children are waiting on the steps. Some come dressed in their school uniforms, others in casual jeans, skirts or sweat pants, usually dusty and unwashed. Some smell as if they haven't had a bath. As the adult volunteers arrive, the children surround them, grab their arms, and accept the offered kisses on the cheek. The children and adults are very affectionate with each other, frequently exchanging hugs and smiles. Children call the adult volunteers *Tia Maria* or *Tia Alicia* (Aunt Mary or Aunt Alice), as though the adults are beloved members of their own family. Many times during my several visits to the tutoring project children grabbed my hand as I walked by, invited me to sit next to them and work on their puzzle or help them with math. They put their arms around my waist, or wrap both their arms around one of mine, or play with my hair. I sensed an incredible need to be touched, accepted, and loved.

The daily routine begins with unorganized play with jigsaw puzzles appropriate to the first and second graders. After 20 to 30 minutes of doing puzzles, the program director announces that it's time to join together at the front of the room. All the children, about 20 in all, put away the puzzles and sit together in the first two rows of benches. The adult leader starts them doing simple exercises while standing in place, and then leads a series of songs with a religious theme. The children sing loudly and boisterously, if a little off-key. All the children participate in the singing. After about 15 minutes of exercises and singing, the adult leader gives a Bible story with a picture illustration. One

story was about the prodigal son who, after returning to his father, was accepted with open arms. Another day included the story of the one lost sheep that the shepherd brought back to the group. All the stories I heard seemed to have a moral of love, acceptance, and care. After the story is told, a child is selected from the group to pray. Several eager volunteers raise their hand, and one child is chosen each day for the task.

After the story, the children divide up into five groups of three to five children and one adult volunteer. The adult volunteers give the children math problems and puzzles to work on, read the children stories and ask for feedback on the content, ask the children to identify colors such as red and orange, and ask them to write out words and sentences. I was shocked to see the lack of ability in first and second grade school children in basic addition, naming colors, or writing their names. The materials, all provided by the program director, are photocopied copies of math problems, exercises, and numbers. The school work continues for 20 to 30 minutes.

After washing their hands, the children are fed lunch each day, cooked by a community woman who lives next door. A typical meal includes rice and black beans, cooked diced carrots, and a glass of fruit juice. Another menu may be potato soup, half a banana, and a glass of warmed milk. Meals are served on plastic plates and glasses; red, green, yellow and blue. The morning ends with the meal and the children are waved and kissed good-bye as they file out to go home. For them, public school begins in the afternoon.

THE COMMUNITY OF CABASCANGO

At the southern tip of Quito, right at the rural field's edge, sits the neighborhood of Cabascango. It seems that Quito grew southward to include this neighborhood, now part of the urban sprawl. From my apartment in north Quito, I have to drive 50 minutes to reach Cabascango. It is situated directly on the Pan American Highway, which has been recently repaved, making travel north and south easier and faster. Most male residents travel north to Quito's heart for employment, generally by bus.

As in other peripheral areas of Quito, the main street into Cabascango is set with hand-placed stones. The other streets remain dirt -- dusty dirt on sunny days and muddy dirt in rain. There is running water and electricity in the neighborhood, but sewer lines have not been installed. Most homes have latrines in the corner of the lot, outside the house.

Cabascango is less densely populated than other areas of Quito, with houses spaced further apart and many small, family garden plots at the side or rear of the houses. With the gardens are frequently found a few chickens or pigs contentedly searching for food or lying in the sun. Like other parts of Quito, the mostly one-story houses are built of cement blocks, unpainted and gray. Roofs are corrugated fiberglass or traditional red tile. According to the Subcenter of Health, the current population of Cabascango is 4271 residents.

At the far edges of Cabascango, where the city meets the country, cows peacefully graze. Some of the community's women rise at 4 a.m. to milk the cows and sell it locally. Some families also process their milk into cheese, a common pale, white, salty cheese.

There are few businesses present in Cabascango. There is a small general store, an ice cream store, a small restaurant, one mechanic's shop, and a building advertising agricultural products such as fertilizer. There are no health clubs, video rentals, fast food restaurants, or movie theaters in Cabascango.

The culture of Cabascango is typical of the *marginalizados* or marginalized urban. The people are close enough to the city proper to go for employment or buy food and other goods, but far enough away to be separate, peaceful, closely knit, and almost rural. The overall economy is poor with work commonly consisting of simple farming or factory jobs. There are no frills or fancy extras in Cabascango. Like San Pablo, survival is the main priority. The people are all of Spanish mestizo heritage, Catholicism is the dominant religion, and family comes first in importance before community or country.

The Ministry of Health's Subcenter

I heard about Cabascango from an American Peace Corps volunteer who goes there twice a week. She is a nutritionist, in her 50's, married, and speaks very poor Spanish. Her assignment with the Health Subcenter has been to give health talks about nutrition, and she has dug a garden outside the subcenter to demonstrate varieties of vegetables that can be grown. She regularly gives away the produce that she has grown -- lettuce, radishes, carrots, cabbage, and parsley -- which the neighborhood women graciously and eagerly receive. This Peace Corps volunteer was my introduction into the Health Subcenter, its staff and patients.

The Health Subcenter is part of the Ministry of Public Health of Ecuador (MSP), state organized, funded, and operated. The MSP was created in 1967 and has

traditionally had a centralized organizational structure in Quito, with insufficient finances to carry out desired health goals (MSP, 1992). In the past decade finances have dwindled even further. In order to improve real access to health care, augment human resources and community participation, and decentralize organizational decision making, the Ministry has recently begun a seven year project called FASBASE (*Fortalecimiento y ampliación de los servicios básicos de salud en el Ecuador* [Strengthening and amplifying basic health services in Ecuador], 1992) (MSP, 1992).

The goal of FASBASE is to better provide health care to two million of Ecuador's poorest people in 40 health care areas through the construction or enlargement of 155 subcenters, 22 health centers, and 23 hospitals. For every 9000 urban residents, FASBASE plans to provide three doctors, one dentist, two nurses, and three auxiliary health care personnel. The total cost for this project will be 103.2 million dollars (USD), of which \$70 million (USD) will be a loan from the World Bank. There is no mention of how the loan will be paid back. The Health Subcenter of Cabascango is one of the targeted communities for FASBASE funds.

According to the MSP's organizational chart, the *Subcentro de Salud* (Health Subcenter) is the most basic level of health care delivery, in rural and urban areas, offered throughout Ecuador. There are 180 geographically divided areas throughout the country that have Health Subcenters, whose mission is to solve the most frequently encountered health problems and needs (MSP, 1994). The Subcenters refer patients to, and are administered by, the local Health Center, which may be a larger clinic or a hospital. In turn, the Health Centers refer patients to, and are administered by, the second level of

Ecuador's health care, the provincial hospital and administrators. Provincial hospitals, besides providing acute health care, prevention, and health promotion, are supposed to be a reference and provide technical support to the first level Health Centers, as well as supervising and evaluating operations. The third level of health care is the national level, where public hospitals in large cities offer specialty care and supervision to the lower levels of the organization.

One of the problems in the MSP is the excessive centralization of decision making by the administrative levels most removed from the reality of health care delivery. According to the Minister of Public Health, Dr. Patricio Abad (MSP, 1994), this centralization has led to serious distortions in the functioning of the country's health services. It is the MSP's current goal to decentralize health care decision making to lower levels in the organizational chart. According to the MSP (1994), current priority activities for all public health clinics and hospitals are:

1. Pregnancy care
2. Family planning
3. Attention to childhood growth and development
4. Immunizations
5. Prevention and control of acute diarrheal diseases
6. Prevention and control of acute respiratory illnesses in children
7. Prevention and care of accidents
8. Periodic intestinal deparasitization
9. Detection and control of hypertension
10. Detection and control of cervical cancer
- 11.-15. Control of cholera, tuberculosis, malaria, dengue, and rabies.

The list did not indicate the ordering of the priorities.

The Subcenter building is a one story cement block structure with a corrugated fiberglass roof. There is one door into the building which opens onto a small waiting area. The waiting area has three metal chairs, while the majority of the waiting patients stand around the walls. Besides the waiting area, the building contains two doctor's examining rooms, a midwife's examining room, a nurses' office/chart room, a treatment room with small pharmacy, an immunization room, and two bathrooms, one for patients and the other for staff. There is also a small storeroom holding a jumble of paint cans, ladders, sacks, and boxes. The Subcenter is currently staffed by two female physicians, one female midwife, two male medical residents, two female nurses, and three female auxiliary nurses.

On one wall of the nurses' office is a chart listing the 10 primary causes of morbidity in Cabascango from January to June of 1995. They were:

1. Acute respiratory illness	27.7%
2. Malnutrition	27.3
3. Parasites	16.0
4. Urinary tract infections	5.8
5. Lice	5.5
6. Vulvovaginitis	5.3
7. Acute diarrheal illness	5.0
8. Dermatological problems	4.8
9. Ophthalmologic problems	1.5
10. Throat infections	1.1%

This list is representative of the types of health concerns that are treated Monday through Friday at the Subcenter. Additionally, pre- and post-natal examinations, newborn care, immunizations, and health education are ongoing activities.

On my several visits to the Health Subcenter of Cabascango I typically arrived about 8:30 a.m., although there was little activity at that hour. Nursing auxiliaries were arranging charts or cleaning off examining tables, while the doctors and nurses hadn't yet arrived. Patients slowly filled the small waiting area, a few seated but most standing along the walls. Around 9:30 a.m. doctors began seeing patients, after the patients had seen the nurses for vital signs and chart updates. Activity paused around noon, when the doctors and nurses went to lunch, but resumed for the afternoon, until about 4:30 p.m.

Thursday seems to be the busiest day of the week at the Subcenter because it is vaccination day. Many women with babies fill the waiting area on that day, in addition to others waiting to be seen for regular acute health care needs. One Thursday a mother with polio arrives at the clinic, having limped with great difficulty for 30 minutes to get to the clinic. Another woman accompanies her, carrying her baby. She asks the nurse for immunizations, and is told very abruptly that there aren't any immunizations available today, and to come another week. When the mother persists in requesting immunizations, the nurse tells her to wait in the waiting area. The rudeness and lack of courtesy in the nurse's response troubles me and I want to intervene on behalf of the mother. Neither this mother nor the others complain about the treatment they receive. I later ask one of the nurses about the lack of vaccines. She says that currently there is a lack of Diphtheria-Pertussis-Typhoid (DPT) vaccines available from the Health Center

that supplies this Subcenter. Today there is BCG (tuberculosis vaccine) available, but no DPT.

Regularly helping in the clinic are two female community volunteers. One woman is in her 20's and single; she was chosen by the community to work daily in the community pharmacy, located in the Subcenter. The community put up the money to buy the initial pharmacy drugs, and the patients are charged for the medications in order to be able to continue stocking the pharmacy. The volunteer fills the physician's orders for drugs, although she has no formal preparation in pharmacy medicine. I ask her how much freedom she has to decide how to run the pharmacy. She replies, with a grave face looking toward the floor, that the clinic's director, a female physician, decides what to do and tells her when and how. I try to pursue this topic, asking again if she gets to make any decisions, but she again denies the freedom to decide.

The other community volunteer, a woman in her 40's, comes in to help with filing charts and weighing patients. She tells me that she would like to learn to give injections, so that she can help her own family and the community in general. The health care staff decide that she should not learn how to give injections until she has learned some anatomy and physiology. No one is teaching her. During my weeks of observations and interviews in the Subcenter, this volunteer stops coming to the clinic and no one knows whether or not she is coming back. Both these women are excellent examples of community participation, but point to the limited number of community participants and their limited authority and responsibility.

Milly, the Peace Corps volunteer, gives a nutrition talk about once a week, using

produce from the Subcenter's garden to demonstrate how to make a salad, or the importance of calcium in the diet to build strong bones and teeth. Although her Spanish is sketchy and faltering, the patients in the waiting area listen attentively to her words and demonstration, respond to her questions, and generally laugh together and participate in the process. They are respectful of her attempts to educate them, even though she is an American and speaks their language poorly. Not only do they listen, but they gently correct her Spanish, like a mother affectionately teaching her growing child.

On one visit, I go on a home visit with Milly, who has arranged an appointment at the children's hospital in Quito for a child who requires surgery. We walk up dirt roads for about 15 minutes to a small, unpainted, one-story cement block house. There are a dog, three chickens, and a pig in the front yard. The mother greets us and invites us in. The house contains two bedrooms, with at least two beds in each room, a living room and dining room combination, and a small kitchen. There are no doors separating the rooms, only unframed doorways. There is a stereo, upholstered living room furniture, a wooden dining room table and chairs, and a small altar to the Virgin Mary against one wall. The Virgin Mary looks better dressed than anyone in the family. There are two children present, one about 10 years and the other about six months old. It is the six month old who has a jaw deformity which requires corrective surgery.

We relay the appointment information to the mother, who is grateful. She thanks us repeatedly, and asks us to stay for coffee. The mother serves instant coffee in a cup of hot milk, and a bread roll without butter. We chat about her children, her work selling milk, and the upcoming surgery before returning to the Subcenter. A cup of coffee seems

little recompense for the arrangement of the doctor visit, but mutual respect and appreciation has been expressed.

One day late in my visits to Cabascango I look into the midwife's exam room to see a nursing auxiliary printing a large organizational chart for the wall. The director of the clinic, a medical doctor, heads the chart, with the midwife, other doctors, and nurses listed in hierarchical order. Nowhere on the chart is the community council nor the community volunteers listed. I mention this to the auxiliary, asking where the community is included. She replies that this is only a chart for the Subcenter, not the community, a rather telling omission. Milly, the Peace Corps nutritionist, stops by to see what we are doing. When she hears my question, she asks the auxiliary where she, Milly, is located on the chart. The auxiliary nurse laughs as if Milly was telling a joke, which she was not. It is obvious from the chart, as well as from daily interactions, that community participation in daily work and decision making is not a goal of the health professionals. Any input from community members, either individually or as a group, is incidental to the functioning of the Health Subcenter.

THE COMMUNITY OF *FUNDACIÓN APOYAR*

The third community in my study differs from the first two because it is a community formed around a common concern for AIDS treatment in Quito, rather than in a specific geographical location. I believe that it is a community -- a group of people who share a common identity around a private AIDS foundation, whose members have regular interaction at foundation activities, and whose members share a common goal -- AIDS

treatment. However, *Fundación Apoyar* (The Support Foundation) members come from various neighborhoods in Quito. I believe that it is also a poor community. Collectively they have few resources, financial, physical, or in personnel, compared to other private or public organizations, and the majority of the individual foundation members are from poor socioeconomic levels, earning minimum wage or slightly higher.

The Support Foundation was first organized in Quito in 1990, when four HIV positive individuals could find no doctor in Quito who would treat them for HIV/AIDS. They went to the Ministry of Public Health for help, but were told that the MSP only conducts AIDS education and prevention and does not offer health care to HIV positive patients. The MSP has a budget of 140 million sucres (about \$48,000.00) for a 1996 National AIDS Program, money which is being used exclusively for AIDS education and prevention. As a group, The Support Foundation is quite angry about the lack of health care for HIV/AIDS available from the government and from private doctors. As one foundation member put it, "No one wants to know anything (about the problem of AIDS)." Patients, and their friends and family members, feel abandoned by the health care system and, therefore, do not respect the MSP. Another foundation member said that since the government isn't going to offer health care, the patients themselves would create their own.

At an AIDS conference in Quito these four HIV positive people heard an American missionary physician speak, and personally approached him with their request to treat them. The physician started an AIDS clinic in a mission hospital in Quito, and encouraged the four patients to organize their own non-profit foundation for AIDS care. I

heard about the foundation through an American nurse, a friend of mine, who serves on the board of the foundation.

The Support Foundation, like the children's tutoring program in San Pablo, is an example of a non-profit private organization, responsible for its own funding, organization, and operations. A private health foundation can be legally organized with 15 signatures of Ecuadorian citizens and the proper paperwork filed with the MSP.

The Support Foundation consists of a group of voluntary individual members, together called the Assembly, who choose to join the foundation and support its activities. Some foundation members are HIV positive, many are not. HIV status is not disclosed at foundation activities. The Assembly annually elects a Board of Directors, which consists of a president, vice-president, treasurer, secretary, three members-at-large, and three substitute members-at-large. Originally, the organization's statutes required that the president be HIV positive, so that the foundation would stay closely connected to the needs of the persons it was developed to serve. Because this requirement would indirectly require any prospective president to reveal his/her HIV status, the statutes were changed so that anyone could be president. In order to maintain adequate representation on the board by HIV positive persons, a board position was added that would be filled by a representative of the HIV positive support group. HIV positive members of the foundation meet regularly in a support group to offer mutual support, information, care, and medications.

Besides the Board itself, there are four committees of the Board -- medical care, public relations, education, and legal issues committees. Individual volunteers serve on

the various committees, depending on their own interests. One woman, a family member of an AIDS patient, was studying law and agreed to serve on the legal committee. When there are meetings or seminars about patient's rights, she attends the meeting to represent HIV/AIDS patient's interests.

The current foundation president is a woman, a family member of one of the original four founders. Like all foundation members, Board members are volunteers. The only individual who receives a stipend for her involvement is the receptionist who keeps the foundation's office open each afternoon. The foundation's members are motivated to participate in the foundation either because they are HIV positive themselves, or are close friends and family members of HIV positive people. They participate because the government will not or cannot provide for HIV positive people and they feel a need to form their own group, share their own resources, and care for their own needs in AIDS care. Another reason for volunteering given by one volunteer was that, because she is a Christian, she believes that it is her responsibility to offer help to her fellow mankind. She believes that the least the foundation can do is support HIV/AIDS people who are already rejected by their families, employers, the government, and society in general. As is the case in San Pablo and Cabascango, the majority of foundation volunteers are women. When asked why that might be the case, the foundation's president said that many volunteers are single women who have the time to help. She believes that married people are more occupied with their work, family, and the possible objections of their spouse to being a volunteer in an AIDS organization.

The Support Foundation has an office in the old colonial section of Quito. To

find the office, one has to walk or drive up a narrow cobblestone street where there is no street parking available. I parked five blocks away in a garage and walked. Above an arched opening in the building is the name of a funeral home. Through the arched entrance on the first floor I could look into the funeral home office where caskets are displayed. I was impressed with a small casket, the size of a child, that was covered with small pieces of mirror, arranged in a pattern, that brilliantly reflected the gray light of the rainy afternoon. I also wondered how HIV positive patients feel while walking past death's door to get to the Support Foundation -- a paradox. Through the archway, up a short drive, through an open courtyard where cars are parked, into a dark hallway, up a flight of stairs to the second floor, down another short hallway, hides the foundation office. The office was chosen not for its accessibility but because it was cheap. Rent is S/.50.000 (fifty thousand sucres or \$18.00 USD) per month.

The office itself was originally one oblong room that has been partitioned into three smaller rooms. In the first room is a waiting area with three chairs, a bookcase, and a variety of stored items including a black leather doctor's examination table, all very crowded together. The second partitioned room holds a desk, three chairs, and a bookcase filled with books and pamphlets on HIV/AIDS. The receptionist sits here from 2 to 6 p.m., Monday through Friday afternoons, mostly to answer the phone and give out literature. The third room is currently used as a pharmacy, with brightly painted white cabinets along one wall, and several large boxes spilling out all kinds of donated medications. Throughout the three areas the floors are wood, and obviously have not been waxed in quite some time. The three rooms are cold, without any heat source. The

receptionist sits in her coat with a woolly scarf around her neck. The waiting room area is currently used once every two weeks for a volunteer psychologist who meets with patients. Poor HIV/AIDS patients who need to see a medical doctor are referred to a physician with the Military Hospital in Quito, who also volunteers his time. Although medical appointments and donated medications have been offered to AIDS patients for free, the foundation is considering charging S/.10.000 (ten thousand sucres or \$3.50) for each doctor visit, and asking for a donation for the medication in order to increase income for the foundation. Besides a regular medical clinic, the foundation would also like to open a shelter for AIDS patients who do not have housing, usually because they have been rejected by family members.

AIDS patients within the foundation often share whatever resources they have with each other. Besides transportation, food, and housing, they will also share expensive AIDS medications. If one patient dies, the family will often donate the leftover medication to the foundation, or to another patient. If a patient changes medication, the unused pills will be passed on as well. Nothing is wasted, most resources are shared.

There is some participation between AIDS foundations in Quito and Guayaquil, and between the foundations and some private hospitals. For example, if one foundation receives a donation of medications, like vitamins or anti-fungals, they may share those medications with patients in another foundation. Antivirals such as AZT are available in Quito for purchase, but are very expensive, usually beyond the reach of poor patients. One nurse said that an AIDS patient can spend up to \$200 (USD) a month on AZT, plus other drugs, while the average monthly salary is \$170 to \$210. Minimum wage is

currently \$30 a month. The Support Foundation sometimes receives donations of AZT which they can give out free. One month, for example, there were 16 AIDS patients who needed AZT but there was sufficient free medication for only four people. Management of scarce resources is a constant struggle.

The WHO has organized AIDS seminars, workshops, and organizational meetings in Quito, inviting various foundations and the MSP to work together towards coordinating AIDS care and public education. For example, one conference covered pre- and post-test counseling for people taking the HIV test. The coordinated efforts are limited in scope and content. Usually the foundations and the Ecuadorian government operate independently of one another with little mutual interaction. Because of the limited interaction with government health care, The Support Foundation organizes its own activities, both for its own members and in the larger Quito society. One man, a friend of an AIDS patient, was unhappy with the rejection he experienced from the patient's family members. Feeling that awareness of people with HIV/AIDS should be addressed in Ecuadorian society, this man organized a week of cultural events in Quito. He involved photographers, painters, dancers, and the Quito symphony to host a cultural event every night for a week. At each event a small entrance fee was charged, with the money to be divided between The Support Foundation and another AIDS foundation in Quito. Also present at each event was a table with AIDS literature and individuals giving out information and answering questions. At the beginning of each event a five minute testimony of an AIDS person was given personally, or read by someone else, urging the audience to consider their personal reaction to a friend, family member, or work associate

who might be HIV positive. The week's events were well attended; this was the first week of cultural activities around AIDS awareness ever organized in Quito.

A DISCUSSION OF PARTICIPATION IN THREE COMMUNITIES

The Research Questions

The first research question was, "What are the patterns of participation of a lower-class, urban Ecuadorian community when participating with other communities, organizations, and individuals in health care?" In one sense, each of the three communities showed a different pattern of participation based on its location, resources, and health care needs. San Pablo exemplifies participation in a densely populated, low-income neighborhood in a project addressing children's educational and health needs. Cabascango is an urban-marginalized community meeting public health needs through a clinic, and The Support Foundation is a non-profit, private foundation with a different pattern of participation. Each community and its health care program has its own pattern of individual community members and the community as a group participating with health care providers and organizations.

Another way to describe patterns of participation is through comparing my observations with the literature on participation. In general, both San Pablo and Cabascango are examples of what Rifkin (1981) described as public health and health planning approaches to participation. Individual community members participate in their health care to the extent that the professional decides and the client follows the advice. Community representatives in formal health care planning meetings participate as

consultants or committee members with the professional who is the supervisor.

Community autonomy is very limited in both of these communities.

The Support Foundation resembles the community development or self-care approach (Rifkin, 1981). Because of the lack of organized health care available to community members, they have largely constructed their own health care system, small though it may be, to meet their own needs. At times the professional is a consultant to the community which has defined its own health care needs and services, and at times the professional is peripheral to the community. The Support Foundation community has actively and directly created and sustained its own health care services (WHO, 1991). One theoretical way to organize future studies would be to choose only communities that participate in a self-care approach and make comparisons between them.

Additionally, I observed patterns of participation between individual community members and health care professionals receiving and providing health care, between community representatives and professionals in formal meetings, and between the community members and the larger health care system in Quito, including hospitals and the Ministry of Public Health. Participation in each of these three categories varied in frequency, intensity, and duration. I defined frequency as how often an interaction took place between the community and the health care sector, intensity as the significance or importance of the interaction to the community participants, and duration as the amount of time each interaction consumed.

In all three communities, interactions involving individual clients or community members and professionals varied in frequency from five days a week, in the case of

Cabascango, to once a month in The Support Foundation. Frequency of interaction depended on the needs of the individual seeking health care or the motivation of the community volunteer or representative. The intensity of each interaction ranged from mild to strong, depending on the severity and extent of the client's health care needs. The intensity of interaction was the greatest among The Support Foundation clients who had the most physical, psychological, and social needs. Interaction duration varied from 15 minutes to two and a half hours per interaction. The longest duration of interactions, between individual clients and professionals, was in San Pablo where children were with the adults two days a week for two and a half hours each day.

In the category of the community group participating with professionals in formal planning or administrative meetings, the frequency of interactions was less. Frequency varied from once a month to three times a year. Intensity of the interactions also varied, depending on the perceived importance of the issue or reason for the meeting. For example, the monthly community board meetings with the clinic staff in Cabascango were relatively mild in intensity since the issues revolved around routine clinic operations. However, meetings between The Support Foundation board and health care professionals were of moderate to strong intensity when discussing limited financial resources and differences of opinion about how to use finances. The duration of most community and professional interactions was between 30 minutes for more informal interactions to four hours for official board meetings.

Although I had planned on observing several meetings between community and health care representatives, meetings were held infrequently, limiting me to one in each

community. When the community did meet with health care professionals, it was usually just a small group of community representatives who met with health care representatives. In community/health care meetings in Cabascango, five to ten community leaders met every month for health care planning meetings, although the professionals expected 18 community representatives. Meetings in San Pablo usually included about five community members, and eight community members attended regular meetings of The Support Foundation. Although their numbers were small, those present at meetings spoke for the community as a whole.

In the third category of participation, interactions between the community and larger health care systems, the frequency, intensity, and duration of the interactions were all minimal. Little time was spent in planning or evaluating health care relationships between any of the three communities and local hospitals or the Ministry of Public Health. In some cases the community sought more participation but the institution did not respond, and in other cases the community did not seek participation. For example, representatives of San Pablo met once a year with representatives of the local hospital that sponsored the health care program. The interaction was low in intensity, mostly for the purposes of being sociable and polite. The Support Foundation did not meet with the Ministry of Public Health at all and, in fact, completely avoided such contact.

The less frequent, intense, and lengthy the interactions between the community and health care system, the less participation in health care planning occurs at both individual and group levels. The fewer the interactions, the less the individual or community feels invested in the health care program, its needs, activities, or goals.

Comparing the data from these three communities shows that when the frequency of community to professional face-to-face contact increases, even when the interaction is of mild intensity and shorter duration, then interest in health care delivery increases, prompting more participation of individuals and groups.

Additionally, community members become more interested in participation even when interactions with health care professionals are for reasons other than health care. For example, the director of the children's tutoring program in San Pablo lived in the community for one year and interacted with many community residents. Although many interactions were not related to health care delivery, they enhanced the relationship between the director and the community that formed the basis for later participation within health care delivery. The more frequent, intense, and lengthy the informal or personal interaction between professionals and community members, the greater the amount of participation in health care. Informal community to professional interaction is not recorded or discussed in the community participation literature. Therefore, it is not known what impact informal interactions have on more formal participation at meetings or in health care delivery.

The second research question asked, "Who in the community acts on behalf of the community and how do they demonstrate participation?" As I already mentioned, in formal meetings between the community and health care organizations, democratically elected community representatives met with appointed health care providers, who were usually the medical and nursing director of the health care program. The elected representatives spoke on behalf of the community and health care employees spoke on

behalf of their funding agency, the hospital, clinic, or Ministry of Public Health.

Community representatives had been charged to work for the common concerns of the community, including health care, and were considered by health care professionals to speak on behalf of the entire community. In these communities as well as others in which I have worked it has been assumed that community members who attend meetings with health care professionals represent the community as a whole. While this may be partially true, no one individual or small group of individuals can completely represent a community. Not all community members completely agree with plans or decisions of a representative from the community, or with plans made at administrative meetings of the community or of the health care system. I was unable to observe interactions between community representatives present at these meetings and community members at large to see if there were discrepancies in how the community representatives spoke for the community versus how other community members felt. I assume that representatives who did not accurately represent the community would not be re-elected, but I was not able to observe what happened in specific cases of mis-representation. It would require further study to understand how elected individuals who represent the community speak for the community, how accurate or complete that representation is, and what happens within the community when community representatives do not adequately represent other community members.

Additionally, I observed examples of individual community members expressing an opinion or request that was considered by the health care providers to be a request from the community, as though individual community members could speak for the

group. I interviewed community volunteers who sometimes used "I" as the subject of their sentences, such as, "I work in the clinic because I want to help others," and sometimes they used the subject "we", such as, "When the clinic staff need something, we decide to get it for them." Individual community respondents sometimes spoke for themselves and sometimes spoke collectively for the group. The degree to which the individual community member was respected or esteemed by the health care providers was directly related to how seriously their request or comment was received and addressed. In other words, a community member, if socially accepted by the health care providers, could make suggestions on behalf of the community without having any elected or designated position within a formal community organization. This points to the informal organization of a community in comparison to the more formal organization and management of health care institutions. Generally those who speak on behalf of a health care organization are those who have been appointed to positions of decision making authority while those who speak on behalf of the community may be any community member. Which individual or small group best or most accurately speaks for the collective? I believe that they all do and yet none does completely. The community is more than the sum of the individuals who form the community or speak for it. Rather, it is the entity that is formed by the interactions of all its members. During data collection and analysis, I was constantly moving back and forth between focusing on the individual and the group, what each said and did individually and collectively.

The third research question was, "How does participation change over time? I was unable to observe participation at different stages of health care delivery -- planning,

execution, and evaluation stages -- so I cannot fully answer this question. However, I did observe the effects of change in health care personnel and programs on the amount of participation that occurred. In these three communities, changes in health care personnel or in health care programs had a detrimental affect on participation. When the San Pablo school principal was replaced, for example, there was less participation between the school and the health care program for several months until the new principal became acquainted with the program. In Cabascango, when the medical director went on maternity leave and another physician took her place, participation sharply declined for several weeks until the community and physician became more comfortable with each other. There appears to be an important link between the continuity of formal and informal relationships between health care professionals and community members and the amount or degree of community participation present.

Likewise, when the organization of health care delivery is interrupted or changed significantly, participation decreases until the community learns the new system or can accept the changes. Examples of changes in health care delivery are new programs implemented by the Ministry of Public Health every four years when the political administration changes, cessation of the tutoring program for the summer, or a new clinic opening for AIDS care. The more changes that occur over time to health care personnel or programs, the more interruptions there are in community participation. Conversely, the greater the degree of continuity in health care personnel and programming, the greater the degree of participation.

The fourth and last research question was, "What are the indications and

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mechanisms of community dissension or refusal to participate with health care providers or organizations?" What is the opposite of participation? Unbeknownst to me at the time of data collection, The Support Foundation was a good example of a group of people who had refused to participate with established private and public health care systems because those systems were not providing for community needs. Instead, the group formed their own private foundation, their own AIDS health care system, and they collaborated or interacted with a private hospital's AIDS clinic. In the short term, it appears that The Support Foundation has been successful in obtaining health care, but at what may be a high cost in the long term. Because they have refused to participate with the public health care system that was perceived to be inadequate, they have effectively cut themselves off from future possible sources of public funding. For example, The Foundation currently has no money to purchase AZT or organize housing for homeless AIDS persons and will not be receiving funding from the MSP to assist in these needs anytime soon. I am not certain whether the community's efforts to be independent, autonomous and self-caring are worth the loss of potential resources from the public health care system. It is also possible that the public health care system has been weakened by the loss of Foundation members who have taken their own intrinsic strengths and resources out of the public system in order to start their own private foundation.

While The Support Foundation is an example of an entire community refusing to participate, there were also examples of individual refusal. When an individual chooses not to participate, he or she does so by simply not attending the clinic or planned health

care meeting. Since community participation is largely voluntary, there are no formal sanctions for community members who decide not to attend a clinic appointment, community or health care planning meeting. In Cabascango, most women did not act on the invitation to attend women's club meetings, to the disgust of the health care providers. When I questioned some of these women about why they did not attend, they said that the club was a good idea but it was not being held on a day or time that was convenient. They perceived that the day and time had been chosen at the convenience of the health care providers, who also decided the agenda for the meetings. Similarly in San Pablo, although parents were invited to attend informational and planning meetings for the children's program, very few parents attended. Their reasons were lack of time to spend on meetings and the need to work in order to survive financially. No respondent was against the idea of having a meeting or the importance of having community meetings, but they said that it was practically impossible due to work and family demands.

A Lack of Participation

What is most conspicuous in the data around the phenomena of participation is the overall lack of community participation in health care delivery. Contrary to the WHO theoretical definition of participation, poor urban communities are rarely involved in planning, implementing, and evaluating health care delivery. In the case of the Ministry of Public Health clinics, the community is not asked to participate in decision-making at all, only expected to cooperate with plans already made by Ministry professionals and politicians. In the case of San Pablo, a NGO program, participation was requested from

the program's inception, but little community involvement was evident. The community of The Support Foundation was so enraged by the lack of health care offered by the public health care system, private doctors and hospitals that they abandoned those systems in order to create their own, perhaps the ultimate example of non-participation with established health care. As mentioned earlier, there was only one meeting between community members and health care professionals in each community during my period of observation. The lack of such formal meetings is an indication of the lack of community participation in health care planning.

The most commonly stated reason for the lack of participation is financial. Individual community members and community councils have few financial resources to contribute, little free time to volunteer, and are generally consumed by working long hours in order to support their immediate families. Community concerns have little priority in the face of insurmountable personal financial needs. It is precisely within poor communities, where health care needs are greatest, that the fewest community members are able to participate.

A Lack of Power. Because of severely limited financial resources, poor communities also have limited political power. Health care delivery at the community level involves local, regional, and international finances and, therefore, local, regional, and international decision makers. Those who control the finances also control how finances are used, distributed, and paid back in the case of international loans. In the example of the Ministry of Health clinic in Cabascango, the World Bank and other funding agencies have far greater influence in decision making around health care

planning than does the community. The community is generally not consulted. In both Cabascango and San Pablo, health care workers control community meeting days, locations, and times, and they control daily health care delivery activities and plans. The Ministry of Public Health, in the case of Cabascango, and the local funding hospital in the case of San Pablo, control the salaries, health care supplies, and other finances of health care delivery in the respective communities. Because poor communities cannot produce the financial capital necessary to run a health care system, neither are they given decision making authority over health care planning. The challenge of health care and development in poor communities is whether or not those without financial clout will be given any political province.

Another reason for limited community participation in the Ecuadorian context is the hierarchical nature of the society. As the society in general is arranged hierarchically, so are health care delivery systems. The Ministry of Public Health directly controls the actions of its health care professionals, clinics, and hospitals, and indirectly sanctions the efforts of any non-governmental institution or foundation. Politicians take precedence over health care professionals, and professionals over communities. In this class system, poor, uneducated community members, even when acting as a group, are perceived to have little authority, knowledge, or other desirable resources. As such, their participation has little, if any, value and is rarely actively sought.

Groups of people located on, more or less, the same level in the hierarchy or in the same social class have a more participatory style and tend to encourage more mutual input and interaction. For example, the elementary school and the health program in San

Pablo are on the same class level and its participants enjoy equal status with mutual interaction. School teachers give information and referrals about the children to the health program, and the program's staff give feedback to the school teachers and principal. However, participation is severely limited when professionals and communities are socially constrained to participate only with others on their own social level.

An exception to this hierarchical system are the North American health care volunteers who work in Ecuadorian communities. Cabascango and The Support Foundation each have one American volunteer, and in San Pablo four of the adult volunteers are North Americans. The other professionals and volunteers are Ecuadorian. Where there are more North American volunteers -- nurses, physicians, or others -- there is more evidence of a democratic participatory style. This is most likely due to the cultural norms of the North Americans, who value a flatter organizational chart and more participation, even from the poor and uneducated. That the North Americans value a more democratic form of organization, including equal participation with community members, sometimes causes conflict with Ecuadorian health care professionals who do not share that value. While the North Americans seek greater participation, their Ecuadorian counterparts discourage the same, which can make for strained working relationships. Because the North Americans are in the minority within the Ecuadorian health care system, their influence is limited. For example, there are no North Americans in the Ministry of Public Health, so there is little, if any, North American influence at the national policy level.

Participation and Cultural Groups. While mestizo Ecuadoreans and North

Americans were the two most obvious cultural groups present in all three communities, there were members of two other cultural groups living in San Pablo. A few Quichua and African Ecuadorian families were involved in the health program in San Pablo, but only mestizo Ecuadoreans were observed in Cabascango and The Support Foundation. There were no observed differences in participation among the Ecuadorian cultural groups, although that is probably attributable to the small sample size. In the future, it would be interesting to study participation among almost entirely Quichua and African Ecuadorian communities present in Ecuador.

Participation and Volunteerism

In all three communities, while health care providers assumed paid positions within the health care system, community members who participated in health care delivery were expected to volunteer their time and personal resources. Volunteer work has been defined as a form of helping behavior that is nonobligatory and is not done for monetary compensation (Fischer, Mueller, & Cooper, 1991). This discrepancy between paid and unpaid positions in community participation creates major differences between the health care sector and the community in relations of power, influence, and motivation to participate.

I observed that community volunteers were helping nurses in the office with such simple tasks as weighing patients, in the community pharmacy distributing medications, cooking lunch for low-income children, organizing a support group, and serving on a community council or board of directors. International health care literature reports that

volunteers are used in a variety of health care programs. For example, community volunteers have been used in malaria surveillance in Guatemala (Ruebush, Zeissig, Koplan, Klein, & Godoy, 1994), in nutritional monitoring in Jamaica (Melville, Fidler, Mehan, Bernard, & Mullings, 1995), in health promotion for child development in Ireland (Johnson, Howell, & Molloy, 1993), and in the prevention of adolescent problem behaviors in the United States (Allen, Kuperminc, Philliber, & Herre, 1994). Health care programs using community volunteers report varying levels of program success when using volunteers, including lower cost malaria surveillance (Ruebush, et al., 1994), reduced malnutrition among children aged birth to 36 months (Melville et al., 1995), and greater coverage of hospice care patients than before implementing volunteers (Sheehan, 1990).

Unfortunately, little research has looked at what motivates community volunteers to participate in health care (Chevrier, Steuer, & MacKenzie, 1994; Fischer, Mueller, & Cooper, 1991). Some studies reported that volunteer motivators include training and supervision opportunities (Misener & Knox, 1990; Poust, 1990), a personal sense of altruism (Sheehan, 1990), and financial or other incentives (Melville et al., 1995; Shugart, 1992). Chaulagai (1993) reported that urban community health volunteers in Nepal stopped participating because incentives were too small, a lack of time, and no recognition of the volunteer's contribution. Alternately, Atwood et al. (1992) reported the reasons that research volunteers remained in a community-based clinical study of colon cancer prevention: benefit to society, medical benefits to self, and monetary benefits to self. Chevrier, Steuer, & MacKenzie (1994) specifically studied factors affecting the

satisfaction of community volunteers and found a positive correlation between satisfaction and feeling like a team member, receiving feedback from the staff, feeling valuable, and having the volunteer's expectations of participation match the actual job.

Volunteers in the three communities in this study said that they were motivated to help their neighbor or mankind in general, that they received satisfaction for helping, and some reported receiving some financial incentive. One volunteer in Cabascango stopped volunteering because she did not feel included in the group of health care personnel, and she was not being taught some of the basic nursing skills that she wanted to learn. All community volunteers in this study reported some degree of concern for the common good, that they volunteered work time within health care delivery because they could serve the well-being of the group as a whole. On the other hand, professionals reported that they were motivated by salaries and by vocation, or the sense that they had a personal calling to their profession. While the sense of vocation, within the Ecuadorian context, includes some degree of service to mankind, the larger motivation for professionals is personal gain, not the common good of the community they serve. The differences in motivation for volunteers and professionals may be the single greatest factor in predicting participation between communities and health care professionals.

Although all volunteers were from lower socio-economic levels, almost all the volunteers that I observed or interviewed were women. Other studies using community volunteers report that more women than men volunteer, and that men who do volunteer drop out in greater numbers than do women (Chaulagai, 1993). Also, according to the literature, male community volunteers respond to different motivators than female

volunteers. Men tend to volunteer for more recreational and work-related activities, while women volunteer for more health and education activities (Romero, 1986). This is consistent with my finding that, almost exclusively, women were involved as community volunteers in health care delivery in Quito. Also consistent with my data is Fischer, Mueller, & Cooper's (1991) observation that a large portion of volunteering is actually done by a very small proportion of the community.

There are some dangers or potential problems with assuming that community volunteers ought to participate in health care delivery with paid health care professionals and organizations. Utilizing unpaid volunteers reduces the obligation of the health care system to adequately meet client and societal needs. To what extent should community volunteers be expected or obligated to fulfill health care expectations that are not currently being met by professionals and health care systems? For example, Shugart (1992) stated that volunteer visitors were used in a home health care agency because of program under funding and a shortage of health personnel. McCann & Wadsworth (1992) pointed out that, with AIDS care shifting from the hospital to the community, it is unpaid informal care givers who sustain care giving and who feel under supported physically and emotionally. Is it justifiable to require health care services from unpaid community members when the potential for exploitation is so great?

Expecting volunteers to perform services that have previously been expected of the health care system places an undue burden on informal volunteers. Since more women volunteer in community health care, the potential for exploitation is increased. Many women have time available for volunteering because of limited opportunities for

paid work. Rather than increasing their potential for economic improvement, volunteering may further jeopardize their work in the home or with their children. This may be particularly problematic for poor women who are already at risk due to a lack of financial resources.

When using volunteers there is great potential for conflict between the community volunteer and the professional. Frequently I observed that professionals, because of their status in the health care system and their personal pride, did not want to share their authority with the volunteer. Apparently the presence of volunteers threatened the professional's personal power. For example, in Cabascango a community volunteer ran the small community pharmacy that was located in the clinic. Throughout my observations, it was the clinic director who told the volunteer how to arrange the pharmacy, when the pharmacy should be open, and how to operate the pharmacy, all decisions that could potentially have been made by the community volunteer or a community-organized committee. This attitude did not encourage increased participation by the community volunteer.

Another problem perceived by the professional is the unreliability of volunteers. Because they are volunteering and, therefore, not obligated to arrive at a certain time or fulfill a certain job description, volunteers were often labeled unreliable. This was a further source of conflict between the professional and volunteer.

A larger issue with community volunteers is whether or not they should substitute for government entitlement programs. By utilizing community volunteers, are we reducing the obligation of government toward the disenfranchised? For example,

Misener & Knox (1990) reported that Community Health Army nurses numbered between one and four for every 150,000 population, and were unable to meet the need for postpartum home visits. They recruited volunteers to try and meet the health care needs of their population. The Army is only one specialized branch of the government's obligation for health care but is an example of insufficient resources applied to health care needs. In San Francisco, CA, a coalition of volunteer physicians, nurses, and hospitals coordinated free outpatient surgeries for patients too poor to pay and not being served by government programs (Schechter, Grey, Burik, Caldwell, Elder, Neumann, & Hofmann, 1995). It is no more reasonable to increase the burden on health care providers than on community volunteers when the government has failed to care for health care needs. If volunteers, professional or community, are going to assume some of the health care needs of the population, then government should also address how those volunteers will be supported.

CHAPTER SUMMARY

In this chapter I described three low-income urban communities in Quito and the health care project or system that exists in each. I addressed the research questions about patterns of participation, who speaks or acts for the community, how participation changes over time, and what are the indications of refusal to participate. I concluded that the more frequent, intense, and lengthy the interactions between community members and health care providers, the greater the amount of community participation that will occur. Interactions include non-formal or social exchanges as well as formal health care

contacts. I also described some of the reasons for the lack of participation -- limited financial resources of the community members, their parallel lack of power or influence on health care at the local level, and the formal hierarchy of the health care systems in Ecuador that limits local, voluntary community groups from acting in organized health care.

Finally, I discussed the presence of unpaid community volunteers within a health care system that pays its health care professionals. Women community members volunteer more often than men do in health care and volunteers are increasingly seen as a way to extend health care services not currently offered by professionals. The potential for exploiting community volunteers is great and should be evaluated whenever volunteers are included in health care delivery. Additionally, volunteers should expect to work alongside health care professionals who are reluctant to share their authority or power in decision making. Within society as a whole, the balance between the responsibility of government and of volunteers to provide adequate or complete health care should be evaluated and addressed in more global terms.

In the next chapter, I look more specifically at the question of gender in participation and present a grounded theory of community participation in Quito. I propose that poor urban communities are acting in "female" ways, within a society that contains many *machista* relationships, in order to manage power imbalances and achieve health care goals.

CHAPTER 5

RESPECTING AND LOSING RESPECT:

MACHISMO AND COMMUNITY PARTICIPATION

Community participation occurs whenever the health care system comes into contact with the community, the community as individual recipients of health care and as a collective that desires the presence of health care delivery in its midst. Most typically, CP takes place when health care personnel interact with community members in a hospital, clinic, or other delivery setting. Participation also takes place in formal and informal meetings between representatives of the health care system and of the community.

The process of community participation in Ecuador is conditioned by several sociological factors. Poverty is one factor. As poor communities struggle to survive and provide for basic needs of shelter, jobs, electricity, and water, to name a few, little energy or time is left for CP in health care delivery. The presence and influence of foreign and national health care organizations, such as the Pan American Health Organization, Ecuador's Ministry of Public Health, and NGOs, also provide a context for CP in Ecuador. These organizations influence health care decisions on local and national levels through their financial allocations and centralized structure for decision-making. Likewise, Ecuadorian culture attributes meaning to health and well-being, professional roles, and interpersonal interactions within health care systems, further shaping CP. Within the hierarchically arranged social stratification of Ecuador, professionals are

assigned more value and authority than lesser educated community members. All of these contextual factors -- poverty, lack of education, outside health care funding agencies, professional pride and power in a hierarchical society -- contribute to a basic and dramatic imbalance of power and influence between interacting community members and health care providers. Community members are invited to participate in health care, but if and when they do participate they are frequently relegated to the position of volunteer or token representative. They are asked to agree to plans and activities that have mostly been decided beforehand.

SELECTION OF THE FRAMEWORK

I considered analyzing the data from the perspective of power and power imbalances, a critique of power in participation or the possibly oppressive nature of health care providers' influence over poor communities. However, the respondents themselves did not talk about power relationships nor about oppression and I used a grounded theory method of analysis where the respondent's point of view is the determining analytic criteria. While others might have used a critical social perspective or some other analytical framework, I desired to accurately depict, as much as possible, the respondent's perspective. I chose to represent what the community members expressed rather than what I might have expressed from my own social and political background. Had I represented this data in terms of oppression, paternalism, or other theoretical construct of my own invention, then as a researcher I might be perceived as being as oppressive or paternalistic as the health care providers who I criticize. Being a

researcher gives a certain power to decide how I will represent the research participants. Additionally, I decided that analyzing the data as oppression or paternalism in a social critique would do little to help me understand how low-income, urban communities participate in oppressive or paternalistic contexts, nor how to change or influence current patterns of participation, beginning with how participation currently happens. At heart, I am a pragmatist. Rather than alienating health care providers by labeling them oppressive or paternalistic, I would like to understand both health care providers' and community members' current styles of participation, deconstruct them, if you will, in order to initiate change from this understanding. Therefore, I view the power imbalances between community members and health care providers to be the context for what is currently happening in participation. I asked myself, within the context of poverty and powerlessness, how do community members and health care providers interact or participate?

In San Pablo, I noticed immediately the number of women who were participating in health care. The number of both professional and community women involved in health care delivery greatly outweighed the number of men. I first wondered if community participation was largely a woman's role in society, for both professionals and community members, and began formulating a theory of participation as a female-gendered role, similar to the role of women in the normally male-dominated or macho Ecuadorian family. For example, schools, clinics, and hospitals organized by men were more hierarchical in organization, used more formal titles and positions for their members, exercised more overt authority, and were generally more adversarial in their

relationships with other organizations or communities. I labeled these behaviors a male participatory style. Local health care workers and community groups that largely consisted of women had a flatter organizational chart, used informal or family titles for their members, exercised more informal or covert means of influence, and were more cooperative than competitive in their operations, a more female participatory style.

When I entered the second community I had to modify my impressions when I saw professional and community women operating in what I had labeled a male participatory style. For example, some female nurses and physicians exercised their authority in much the same way that men had in the first community. However, as compared the two communities, I realized that what I had labeled as a female participatory style was still generally true for the community as a collective, and the male participatory style was generally true for health care professionals as a group. Rather than seeing participation as gender specific, I wondered if a poor, urban community acted in a female way within Ecuadorian society. When talking with respondents about male and female social roles in Quito, the discussion invariably included comments about *machismo* or the roles, behaviors, and attitudes expected of male and female individuals. Regularly, in my personal and professional life, I heard the term *macho* applied to a person's way of doing something, or to the person himself, usually a male. I wondered if cultural expectations of *machismo* could be applied to expectations of people in collectives.

As I continued to analyze male and female participatory styles as compared to health care providers and communities, I reviewed health care and sociological literature

around gender roles and the concept of *machismo* in Latino cultures. I concluded that *machismo*, as used in Ecuadorian culture, is a theoretical framework that is not only applicable to individual male-female relationships within families but also to relations among and within groups. Since *machismo* is about power differentials between men and women as well as about social role expectations, the concept seemed to mirror the power differences I had already observed between communities and health care providers. I propose that much as males and females in Ecuadorian families interact in *machista* ways, so do health care professionals and poor, urban communities interact, with the professionals taking on the role of male (*macho*) and the community the role of female (*hembra*). In this view, *machismo* can be practiced by female and male health care providers with poor, urban communities, and responded to in kind by male and female community members and by the community as a group. As I sought verification, these ideas were supported again and again by both community members and nursing colleagues.

Machismo, like any other theoretical concept, is a set of abstracted or generalized beliefs, values, and behaviors. There is no one health care provider, or group of providers, that completely exhibits *machismo*, just as there is no one male who completely exhibits all *machista* values or behaviors. Nevertheless, the concept is used daily in Ecuadorian vocabulary and it appears repeatedly in the social science literature as a primarily Latin American phenomenon (Ramírez & Arce, 1981). It is one way to understand roles, social expectations, and power differences between people.

The conceptual framework of *machismo* is likely to be problematic for some

scholars because it has been equated with male chauvinism and male dominance of women in Latin American cultures. The concept brings with it a contested history. Mirandé & Enríquez (1979) argue that, in largely unsubstantiated writings, social scientists have traditionally characterized *machismo* as a universal stereotype and have blamed the existence of *machismo* for many maladaptive, pathological responses, particularly by Latin American immigrants to Euro-American cultures. The *machismo* stereotype is the phenomenon of the man as lord and master of the household, with the woman relegated to an insignificant, subordinate position (Miller, 1978; Mirandé & Enríquez, 1979). Besides absolute patriarchy, *machismo* traditionally stresses exaggerated masculinity and sexual virility (Ramírez & Arce, 1981). Men prove their sexual prowess through courtship rituals and extramarital affairs, while women are not allowed the same liberty. The woman's role in stereotypical *machismo* is tied closely to her marital status and work within the home (Mirandé, 1977; Mirandé & Enríquez, 1979). *La hembra*, as wife, mother, and daughter, is treated as a saintly, virginal figure to be protected, idealized, revered, and held on a pedestal so that she is kept out of the reach of male predators (Neuhouser, 1989). Mirandé (1977) believes that these stereotypes have been created by social scientists unfamiliar with Latin American culture and eager to pathologize another culture. Using *machismo* as an organizing theoretical framework may be seen by some as an approval or validation of the concept. It is not my desire nor goal to reinforce stereotypes of *machismo*, nor to eulogize it as a quaint, cultural artifact. However, I would argue that in the Ecuadorian context it exists and is understandable to the respondents in this study. For them, *machismo* provides a common and

understandable vocabulary from which to discuss issues of roles, status, position, and power -- all components of participation. Therefore, using *machismo* as a theoretical reference point is a good fit for this data.

The concept of *machismo*, as present in Latin American culture, is better defined in terms of family pride, respect, loyalty, responsibility, and trust rather than in terms of male dominance (Mirandé, 1977; Ramírez & Arce, 1981). It is more helpful and positive to view *machismo* as a system that has served to protect the Latin American family from destruction during and after the Spanish *conquista*. In this view, *machismo* was a socially constructed set of norms and behaviors designed to balance the unequal power of the Spanish over the indigenous people. By taking on *macho* and *hembra* roles, the family was able to maintain itself and resist at least some of the powerful, and frequently destructive, influences of Spanish colonization. In more contemporary times, Mirandé & Enríquez (1979) believe that *machismo* can be viewed as a manifestation of Latin Americans exerting their manhood and womanhood against the Anglo society that would seek to dominate or erase Latino culture. The *macho* is viewed as actively resisting external oppression and colonization, while the *hembra* perpetuates the cultural values and cohesion of the family. *Macho*, in other words, does not relate merely to manhood but can also relate to nationhood or group identity and well being. It is within this larger sociological and historical context that I view *machismo*.

Like any other cultural concept, *machismo* and respect are not static concepts that always appear the same at all times and places. For example, as Latina women increasingly enter the work force, they enter the public sphere that has traditionally been

the exclusive domain of men. In 1990, throughout Latin America, 32% of the women aged 15 and over had entered the workforce, compared to 80% of men (United Nations, 1991). If women in the informal work sector were included, the percentage would probably be higher. Women who become wage earners increase their influence and respect inside the home (Meleis, Douglas, Eribes, Shih, & Messias, 1996; Neuhouser, 1989).

Although being a wage earner outside the home enhances the woman's power inside the household, her influence and general social position remain very weak. Neuhouser (1989) found that women in Brazil generally received lower wages for the same jobs held by men, and women were far from being equally represented in business administration and government positions. The same can be said for Ecuador where women's salaries are not only lower and their job capacities limited, but they are also expected to maintain their work at home (Toledo Duarte, 1988). In Ecuador, Nela Martínez became the first parliamentary representative of the country following the revolution of May, 1944 (Toledo Duarte, 1988). However, as of 1987, only 1.4% of parliamentary seats were occupied by women, and no women were present at the ministerial level of government (United Nations, 1991).

As Mirandé & Enríquez (1979) view the use of *macho* and *hembra* roles as a way for the Latino family to survive in a hostile environment, I see community and professional behavior in a hostile environment of poverty and as a way to maintain health care services. There are many examples in the data where communities act in *hembra* ways, respecting health care providers and, in turn, expecting them to care for or provide

for the needs of individual community members and the community as a group. For example, in San Pablo, the teachers mentioned the health needs of the children: measles, lice, intestinal amoebas, and the need for psychological counseling. They appealed to the health care program director for help with these problems, trusting her to provide for the children. The teachers also mentioned the lack of response to these health needs from the Ministry of Education. They said that they could use a full-time counselor or psychologist but, "What do they get? Nothing," they said.

In Cabascango, the clinic hours posted on the wall read 8 a.m. to 4:30 p.m., yet it is around 9 a.m. before the nurses and doctors arrive, and 9:30 a.m. before they are ready to see patients. The patients, on the other hand, begin arriving at 8:30 a.m., waiting in line to see the doctors. The patients do not seem annoyed by having to wait an extra hour to be seen by the physicians. They wait patiently, quietly, without voicing a complaint. Patients trust and respect the health care professionals and demonstrate that respect by waiting on the goodwill of the health care provider. The health care providers, on the other hand, set their own work hours and routine irrespective of the community members, as though that is their right as professionals. While health care providers have a responsibility to care for ill community members, they also have the privilege of deciding how and when they will do so, a typical *macho* power arrangement.

The community of Cabascango is proud to be a part of the FASBASE project, perceiving that the MSP is taking care of them with this expansion project. When asked, the community residents say that they do not know how the World Bank loan will be repaid, but they do not think that it will affect their personal economy. It will be the

responsibility of the government, *el macho* in this case, to take care of present health care needs and future loan repayments.

The very existence of private foundations, as is the case of The Support Foundation, seems to be based on the inability of the health care system to provide for the needs of all Ecuadoreans. The *macho* government has failed to provide for all groups, necessitating that groups of people with common needs abandon public health care and formulate their own health care delivery. For example, foundation members say that the MSP Provincial AIDS Office accomplishes almost nothing without detailed direction by the National AIDS Office. Since the National AIDS Program only offers AIDS education and prevention, the Provincial office will only offer education and prevention, not AIDS care, a decision that infuriates foundation members.

There are many ways in which health care providers and organizations act in *macho* ways and in which communities, individually and collectively, act in *hembra* ways. This is not meant as an acceptance of *machismo* in Ecuadorian culture as much as a way to understand how poor, urban communities have survived in an otherwise hostile environment of poverty and political powerlessness. Mirandé & Enríquez (1979) wrote that *machismo* was a way for Latino families to survive in the face of powerful colonization; I believe that the same social construction is a way for poor communities to survive and secure health care resources in the face of powerful, internationally connected health care systems. *Machismo* and respect are hereby related to community roles in urban Quito as much as to male roles in a *Latina* family (Mirandé & Enríquez, 1979).

Recognizing the problematic history of *machismo*, a more realistic and usable

component of the theoretical framework is the value of respect in *machismo* and in Latin American culture, respect of the male as the leader and protector of the family. The man is respected, including granting him special privileges, more freedom and authority, in return for which he is expected to provide for the needs of all family members (Mirandé, 1977; Mirandé & Enríquez, 1979). The male is expected to deal justly and fairly; should he misuse his authority, he can lose respect. In turn, the woman provides warmth, support, and affection for family members who must survive an otherwise hostile environment. Women are respected within the home as much as men are respected outside it (Neuhouser, 1989). In this way, respect can be seen as a pivotal concept in understanding the mutuality of the relationship between males and females in an Ecuadorian cultural context. Equally, respect can be an organizing concept for this data about the relationships shared between community members and health care providers.

For example, The Support Foundation does not respect the Pan American Health Organization any more than it respects the Ministry of Public Health. For example, the Pan American Health Organization representative for AIDS in Ecuador once met with representatives of a local hospital that was organizing an AIDS clinic. After discussing the AIDS situation in Ecuador, a hospital physician asked the Pan American Health Organization representative what he could offer the hospital to assist in AIDS care. The answer: some office furniture and perhaps some laboratory reagents. These resources were considered inadequate by The Foundation and contact between The Support Foundation and the Pan American Health Organization has not been maintained. What The Support Foundation wants from the MSP is an organized plan for AIDS health care,

education, and prevention, adequate materials and personnel resources for AIDS care, and some shared power in decision making and funding between public and private sectors.

Showing respect or respecting is the concept that best explains the data around community and health care professionals' relationships and interactions. Respecting health care professionals is a means by which the community can ensure group identity and continuity of health care. In the case of health care needs, respecting is a key theoretical process by which poor, urban communities negotiate for health care resources within a local, national, and international health care system. A poor community has few alternative choices. Individual community members and representatives respect the health care providers in order to assure the presence of health care in their community, to legitimately participate in health care decision making and in care itself. When community members, individually and collectively, respect the health care professionals and health care organizations, the community is allowed to participate in health care delivery. Conversely, health care providers who are respected by the community are expected to provide for the community and for health care needs. Respect for health care providers declines when health care needs are not met.

The following section describes how communities **respect** the health care providers and organizations, **support** health care delivery, and **collaborate** by sharing their own resources. In turn, the health care providers are expected to **provide for** the needs of the community, both for individuals and for the group, **share** health care resources in interactions with the community, and fairly **represent** the community to outside organizations such as the Ministry of Public Health. I also attempt to demonstrate

how **losing respect** for the health care professionals and organizations changes participation within the same communities. Derived from my analysis of the data, these concepts describe beliefs and behaviors that influence the amount of community participation in each community. The relationships of these concepts are depicted in Figure 1, which illustrates the grounded theory that I developed.

RESPECTING

In this study, respecting [*respetando*] means to approve of, give deference or priority to, or to esteem another as having higher status than oneself. In Spanish, to respect means to have awe, reverence, deference or consideration for another (Ruiz, 1989). Communities respect the health care providers and organizations in their midst. Respecting is evidenced in certain behaviors of individual community members and the community as a collective. Related to respecting are supporting and collaborating.

One way to show respect is to use respectful forms of address. When entering a clinic or arriving at a meeting, a community member addresses the professional or health care administrator as *licenciado(a)* [literally, licensed, meaning having a bachelor's college degree], doctor, or other appropriate form of address. In San Pablo, for example, the adults were addressed as *Tía* [aunt] by children, parents, and school teachers alike. Besides addressing them by their correct title, it is respectful to say good-morning or good-afternoon, to stop and shake hands, or nod the head toward the professional. This ritual greeting should be repeated for each individual who is present in the room. Varying degrees of respect can be communicated by greeting persons by their titles but

not stopping in front of them, by not offering a hand shake, or by not greeting at all, which is considered highly disrespectful. Individual patients greet health care professionals within a clinic or other program setting, and community representatives greet health care representatives in scheduled organizational meetings.

Respect is also demonstrated by community members giving priority or deference to the needs and wishes of the health care professional or organization. For example, professionals are more readily excused for being late to a meeting than are community members. Professionals set the agenda for a community health care meeting and are given the best seats in the room for a meeting or a clinic. Even I, a researcher and nurse, was offered a chair in the Cabascango clinic while patients were expected to stand in the waiting room. Professionals organize the physical location of health care delivery and the amount and type of patient care offered. The professionals are not grudgingly allowed to have preference in these areas, but are expected to direct these activities and to take priority within the clinic or meeting because of their status as professionals.

Deference is also demonstrated by allowing and expecting the health care professional to make health care decisions which the community expects to follow. This applies to individual health care decisions as well as decisions for the group. The health care provider has the authority to decide about care with very little patient input. When asked if they want to be involved in decision making, almost all patients said that they did not want to decide, but wanted to follow the decisions of the doctor or nurse who is the expert. The provider also makes most of the decisions for health care delivery within the community -- when and where to offer health care, what health care to offer, and how

it will be organized. For example, in San Pablo the professionals decided what program to give the children, and neither parents nor school teachers disagreed. Likewise, the doctors, nurses, and midwife in Cabascango decided to hold a women's club every two weeks. Community women were invited to attend the meeting and while they offered some ideas about when they wanted to meet, all major decisions were made by the professionals. Deference to the wishes of the professional is one sign of respect.

Supporting

Respecting is further demonstrated and verbalized by supporting [*apoyando*] health care plans. Supporting was usually expressed verbally as defending the health care professionals or organization, or praising them for their work. For example, a community member in Cabascango said, "The [clinic] director says, 'We are going to buy such and such a thing,' and we support her." A mother in San Pablo said, "My daughter is fine here and I am happy. I greatly thank the *señorita* because she has a lot of patience and she teaches them with a lot of love." A school teacher in San Pablo stated, "We think that the *Tia's* program helps us a lot in the teaching process with the children." Repeated verbal approval and praise are signs of respect and were mentioned as signs of support by community members.

Collaborating

Collaborating [*colaborando*] with health care delivery was usually expressed by examples of sharing community time and resources, including financial resources. In San Pablo, the children's family pays a daily fee for the program, the local teachers share information on their students, the church donates the building, and a neighbor woman

cooks lunch for the children, all examples of collaboration. In Cabascango, community funds paid to have the road fixed, for the purchase of furniture for the clinic, and for the initial drugs to stock the community pharmacy. Community leaders and others volunteered time for a *minga* [community work day] to paint the clinic. In The Support Foundation a community volunteer acts as receptionist at the Foundation's office, members lend their homes for meetings, and members mutually share food, AZT, antibiotics, and other drugs. All board members volunteer their time to The Foundation as well. These are examples of collaborating with health care organizations and providers in the delivery of health care services and programs and of showing respect for the professionals and the organization as a whole.

Respect varied in intensity in the three communities. I observed the greatest amount of respect toward the health care providers in San Pablo, where no one had a negative word to say about the health program, the professionals involved, or the hospital organization that sponsored the program. In Cabascango, respect was shown toward individual professionals in varying degrees, but respect for the MSP was reserved at best. In The Support Foundation, efforts of both private doctors and the MSP to treat HIV seropositive patients were scorned. One missionary doctor and the missionary hospital's clinic were praised and respected for their solo efforts to treat HIV seropositive patients. Why are some professionals and organizations respected and others scorned? Since the amount of respect demonstrated by community members appears to be connected to the amount of community participation, it is important to understand what engenders respect for the health care professional or organization.

As I mentioned previously, communities respect the health care providers and organizations because they want health care to be present in their community. They give respect, from their relative position of powerlessness, in order to receive health care. However, in return for that respect, the community expects the health care providers to respond responsibly by meeting health care needs. The community respondents in this study described the health care providers' responsibility as providing for the community's health care needs, sharing health care resources, and representing the community and its health care needs to other health care providers and organizations.

PROVIDING FOR

Although health care professionals are immediately respected by community members because of their social class in Ecuadorian society, they must meet perceived professional obligations in order to maintain or increase respect. Also, professionals can lose respect by not meeting their obligations or responsibilities. In this study, the main process by which professionals engendered or maintained respect with poor, urban communities was by **providing for** the needs of the community, both individually and collectively.

Health care professionals provide for individual patients when they offer consistent patient care in the community, when they assist patients in solving problems of access to other health care not provided within the community, and when they assist with other health and social needs such as food or clothing. Consistent patient care may seem to be an obvious professional obligation, but there are instances when care is not

consistent and professionals lose respect. For example, the physicians in Cabascango lost respect when they went on strike with others within the MSP over a wage dispute. Their leaving closed the clinic and left the community without health care for a month. Private physicians and the MSP National AIDS Office lost respect with The Support Foundation when none of them would offer complete and compassionate care for AIDS patients. The patient's response was to organize a foundation for their own health care.

Professionals provide for client needs when they work with clients in solving health care problems, usually problems of access to specialized care or some service that is not offered locally. The director of the children's program in San Pablo regularly scheduled visits with ophthalmologists, psychiatrists, and other specialists based on the needs of individual children. This was viewed as providing for the client, and won further respect for the program and its director. One mother whose child with special problems said, "The *señorita* has helped me a lot. A great deal she has helped me," referring to doctor's visits and special teaching offered. The Peace Corps volunteer in Cabascango made an appointment with the surgical service of Quito's children's hospital on behalf of a community mother who didn't know how to work the system. The mother was very grateful for the appointment and subsequent surgery and demonstrated her respect by inviting the volunteer over to her house for coffee and bread.

Health education is also viewed as an extra service provided by professionals that is appreciated and respected. I observed health classes in first aid, amoeba prevention and treatment, and nutrition in which community members participated with interest and appreciation that seemed to exceed the actual service offered. When I asked a community

organizer in Cabascango why health education was so appreciated, he said that since there were so many illiterate people in his community they needed the knowledge and instruction of the professionals.

Additionally, professionals provide for other health and social needs, such as food and clothing. In San Pablo, the children's program regularly gave school supplies to the children, and at the end of the year gave each child a pair of new school shoes for the following year. Among members of The Support Foundation, I heard stories of shared housing, food, and medications that resulted in a great deal of respect for professionals.

Professionals also provide for community needs in collective ways, by organizing and supervising health care delivery, a woman's club, or an AIDS awareness week, and by participating in non-health care activities such as a church or other civic event. In Cabascango, the clinic physicians worked with the community to stock a community pharmacy, staffed by a community volunteer, that dispensed medicines to clients during regular operating hours at the clinic. At monthly meetings between health care providers and community representatives, the community members feel that they can "take whatever *inquietud* [apprehension, concern or worry] and ask for support and help" from the professional. In The Support Foundation, nurses worked with community volunteers and AIDS patients in organizing the first AIDS Awareness Week in Quito. There were cultural events each evening during the week, such as an art show or a coffee-house concert, where AIDS information was distributed and someone with AIDS gave a personal testimony in person, by tape recording, or in writing. The Support Foundation members appreciated the participation of the nurses in an activity that was perceived to be

above and beyond normal professional expectations.

Sharing

While providing for client and community needs was the principle process that increased community respect for the professional, I also observed health care personnel who shared resources with the community and were respected for doing so. **Sharing resources** involved contributing their own or the health care program's resources to assist the community or client. Examples of sharing resources were a nurse giving a patient a ride in her car, a doctor sharing her VCR machine at a community meeting, and a clinic administrator sharing office space for a meeting. Sharing resources was similar to providing for the community's needs, but differed in that the item was not given or donated permanently to the client or community but was shared for a time. Sharing resources also occurred collectively, as when a local church shared its building twice a week, or a hospital shared its clinic space with a foundation.

Representing

A third way that health care professionals increase their respect in the community is by **representing** the community to others outside the community, to other professionals or organizations. For example, one of the nurses at the hospital's AIDS clinic has volunteered to join The Support Foundation's Board of Directors. At Board meetings, she represents the needs and goals of the patients, speaking for them as a group. Similarly, when a Foundation representative goes to the MSP Regional AIDS Office, he or she represents the needs of the foundation's members, soliciting drugs, patient care, or other needed services. The Ministry of Public Health is disrespected because it does not

represent AIDS patients and their needs accurately, as perceived by the patients themselves. For example, the MSP officially says that there are 1,500 cases of persons with HIV in Ecuador. The Foundation believes that the number is 10,000 to 15,000 cases. By reporting fewer cases of HIV, the MSP can justify its lack of response to the AIDS problem, according to The Foundation. Additionally, The Foundation perceives that the MSP has no overall goals or strategies planned for the next year, and it allows each hospital or clinic to do what it wants in AIDS care. A Board member said, "It is sort of like spinning your wheels and not getting very far, whereas if you could get everybody joined together to do something, you might be able to get a lot more done." The Foundation believes that the Public Health Department has done very little to represent the actual life situations or health care needs of seropositive HIV persons to the society at large.

Another example of representing was seen in Cabascango, when school teachers participated in a planned network of schools that wanted to organize specialized resources for children with problems. They were planning an organization of therapists, psychologists, and social workers to help children with learning problems or disabilities. Through these activities, the teachers were representing the needs of the children in Cabascango to a larger network of professionals.

LOSING RESPECT

Unfortunately, as health care professionals can gain respect, they can also lose respect in the eyes of the community. Two examples of **losing respect** have already been

mentioned: physicians going on strike and leaving Cabascango without medical care, and the MSP not faithfully representing seropositive HIV persons to the rest of the country and to international health care organizations. In other words, when professionals fail to provide for, share resources with, or represent the patients or community to others they lose respect.

Teachers at the school lost the respect of some parents in Cabascango when they did not provide for the educational needs of the children. One mother, comparing her respect for the professionals at the children's tutoring program with that for the professional school teachers, said, "The school teachers are despots, rude ones, while here, they are not. Here they are very good and it doesn't compare." Nurses lost respect in the eyes of Cabascango mothers when children were brought to the clinic to be vaccinated and there were no vaccines available. This went on for about three weeks until the clinic was able to get more vaccines from the Health Center. Although the nurses were not directly responsible for the lack of available vaccines, the mothers perceived it as not providing for their children's needs. Fortunately, when vaccines were available, the nurses were able to begin vaccinating again. These are examples of losing respect because health care personnel have not provided for community needs.

There are other ways that health care professionals and organizations lose respect. Professionals and organizations are respected because of their social status and their actions in providing for the community, however, those who abuse the community's respect will lose it. Professionals are given respect, prestige, and deference but they are expected to not abuse that privilege. Professionals and health care organizations, can lose

respect by exerting their authority to the point of **controlling** the community, **blaming** the community for its problems, and **subordinating** the needs of the community to the needs or desires of the professional.

Controlling

Health care professionals and organizations **control** the community when they make decisions with no input from the community, make decisions contrary to the wishes of the community, or manipulate the community or community members. For example, when the professionals at the Cabascango clinic decided to hold a women's club, they announced the day, time, and place for the first meeting, with the organizational help of a male community organizer, but without consulting the women. A group of about 30 people attended the first meeting, a good showing, but no one attended two subsequent meetings. I think that the women attended the first meeting out of respect for the clinic staff, and did not participate further because their opinions, wishes, and needs were not consulted.

Another example of controlling behavior on the part of the Cabascango professionals was the nurse who said, "We motivate them by telling them they have to be vaccinated in order to see a doctor." The nurse went on to describe how they get patients to comply with childhood vaccinations by refusing them doctors' appointments for other ailments until they can prove that the children have been vaccinated. The nurse said that they use a type of threat to get parents to participate in vaccination programs. While these threats may be tolerated by some families in the community, ultimately they decrease respect for the professional.

The MSP National AIDS Office lost respect in the eyes of The Support Foundation when it asked The Foundation to write a grant request for AIDS funding. When The Foundation questioned where the grant money would go should it be awarded, the AIDS Office said the money would go into their own accounts, and could not be awarded directly to The Foundation. The Foundation viewed this as being very manipulative and controlling of funding, and refused to write any AIDS grants.

Blaming

Professionals lose respect when they repeatedly **blame** the community or community members for their problems, rather than seeking solutions to or resolving the problems. In San Pablo, teachers repeatedly stated that the reason so many children had learning problems and were not successful in school was because they came from disorganized homes where there was no father, no discipline, or the parents were uncaring. One teacher complained that although she had reported a child's suspected vision problem to the parents, the parents had done nothing about getting glasses. Rather than seeking solutions for these situations, teachers blamed the parents for health and learning problems. These same teachers were called "despots" by one mother in the community.

Health care personnel in the Cabascango clinic blame community representatives for not attending monthly health care planning meetings on Monday afternoons. One nurse said that one month there are three representatives and another month eight, and these eight are different from representatives present the previous month. "They are not responsible people," she said. Community representatives said that they cannot attend

because they must work Monday to Friday afternoons when the doctors plan the meetings. Members of The Support Foundation believe that individual health care professionals and the MSP blame HIV patients for their disease, using blame as an excuse for not addressing health care needs.

Subordinating

Professionals also lose respect when they place their own desires over the needs or desires of the community, what I call **subordinating** community needs to those of the professional. In San Pablo, the elementary school was closed for two days while all the teachers went to a teacher's training course. A teacher later admitted that going to this course put the children's education at risk, because the children lost those two days of instruction and were already behind in the curriculum. The needs of the children were placed secondary to or subordinated to the needs of the teachers. In Cabascango, the health care professionals decided on the time and place most convenient to them for a women's club meeting and then were disgusted when only three women attended. When I questioned two community members about the meeting times, they said that the best time for the women to meet is on Sunday afternoons, when they don't have to work, but the health care professionals are unwilling to attend meetings on the weekends. Placing their preference first and subordinating the wishes of the community results in loss of respect.

There was one example of community action as a result of losing respect that was particularly noteworthy. The physicians at the Cabascango clinic had decided that one of them would permanently work in another clinic. This decision was made without input

from the community. When the community heard the decision to remove a physician it decided that the clinic was not providing for the community's needs, and that professionals were subordinating the community's needs to their own desires. Respect was lost. Since the community was not asked to participate in the decision, it devised its own form of participation. One Monday morning, during regular clinic hours, a group of about 30 people, men, women, and adolescents, marched up the stone-paved road to the clinic entrance. They were talking, laughing, and eating ice cream cones they had purchased in the shop down the road. They were led by a community organizer who lived in Cabascango. I happened to be standing in the clinic's garden talking with the Peace Corps nutritionist when they arrived and they cordially called out a greeting to us as they passed. The group, although small, was enough to fill the waiting area of the clinic, spilling out onto the cement entrance. I eased my way into the clinic and asked a couple of the participants what was going on. They told me they were *reclamando* [to demand, to claim, to beg] the clinic's decision to remove the physician. Three community representatives entered the office of the clinic's medical director to discuss their grievance. After about 15 minutes, the group quietly left the clinic, with promises that the decision would be reconsidered. I heard two weeks later that the decision was reversed and the physician would not be leaving. Although not asked to participate, the community used group influence to change a decision that they did not respect.

PARTICIPATION AND RESPECT

In an Ecuadorian social context, low-income, urban communities respect health care providers because of the professionals' standing in the social hierarchy and because the community wants continued health care available. Respecting the health care provider and organization is one way to ensure that health care will continue to be available. In return for the respect given, communities expect the health care professionals to provide for the community's health care needs. Additionally, I suggest that the more health care professionals and organizations provide for health care needs, share resources, and represent the community to others outside the community, the more the community respects these professionals and organizations. Respecting and providing are activities that occur simultaneously, over time, and are a result of regular and ongoing interactions between health care systems and communities.

The greater the degree of community members' respect for health care providers, the more the community will participate, both individually and collectively, in further health care planning and administration. In other words, there is a positive relationship between the degree of community respect for health care providers and the degree of participation that will occur. Participation on the part of the community is evidenced by seeking health care from the providers, by attending health care planning meetings, and by supporting and collaborating with health care delivery. The Figure depicts the mutuality of the ongoing interactions between community members and health care providers.

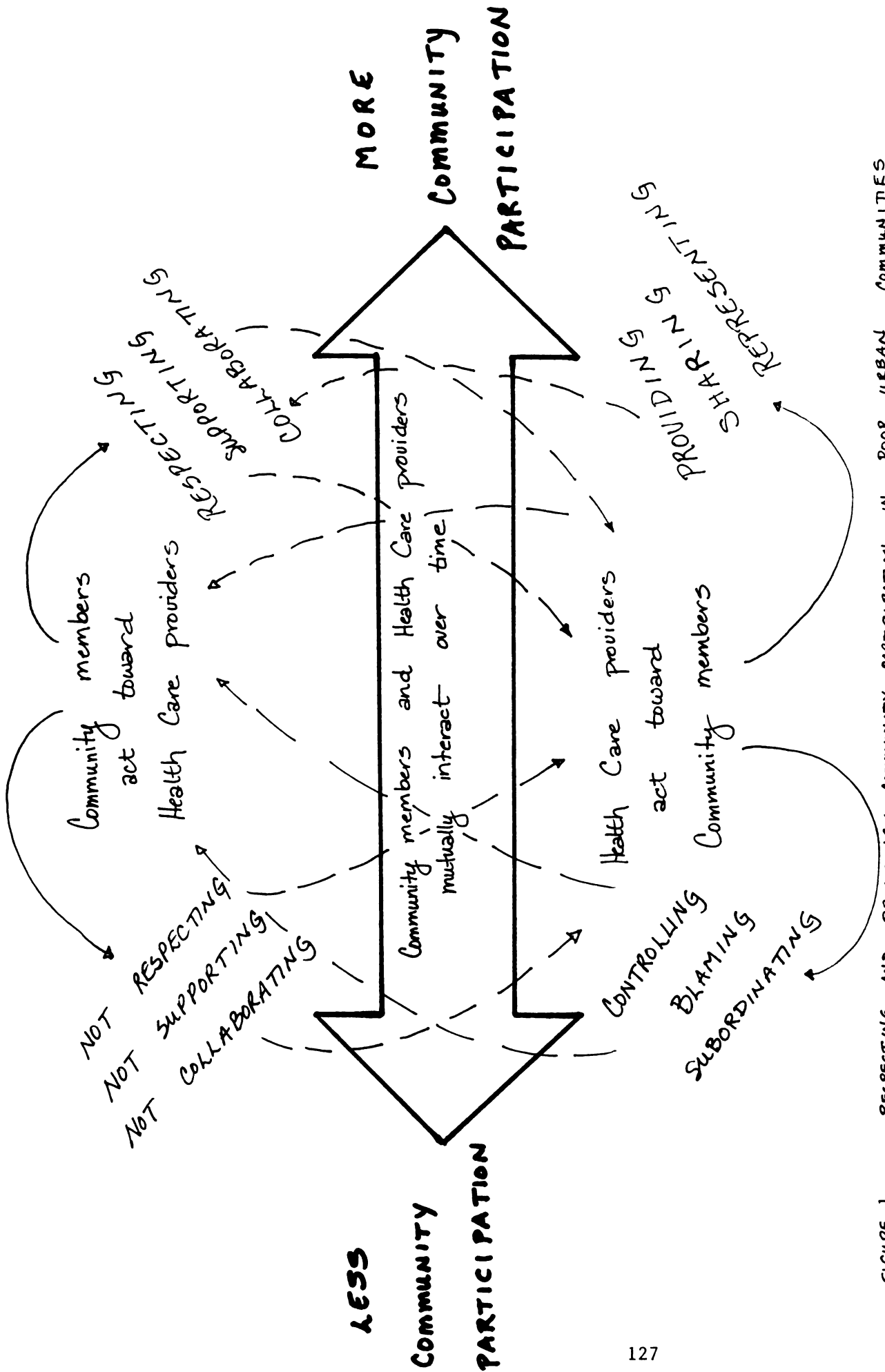


FIGURE 1 RESPECTING AND PROVIDING: COMMUNITY PARTICIPATION IN POOR, URBAN COMMUNITIES

Community members and representatives act toward health care providers and representatives by respecting, supporting, and collaborating in health care. At the same time, health care providers are expected to provide for community health care needs, share their own resources, and represent the community to outside government and health care agencies. The more health care providers provide for community needs, the more community members will respect them. If health care providers do not provide for community health care needs, then respect declines. Health care providers can increase the community's level of respect for them, but they can also decrease their perceived respect by controlling the community, blaming community members for their own health problems, and subordinating the needs of the community under the needs of the health care providers. Additionally, the more health care providers exhibit providing, sharing, and representing behaviors, the more the community will be encouraged to participate. As respect declines so does community participation.

CHAPTER SUMMARY

In this chapter I described how my initial observations of individual women's roles and behaviors in health care mirrored or paralleled the roles and behaviors assumed by poor urban communities. Just as individual women assume certain cultural roles with respect to men in families and in society, I demonstrated that poor urban groups assume similar roles and behaviors toward health care professionals and groups. Borrowing from the theoretical concepts found in Chicano and Latino literature on *machismo* and respect, I framed my analysis around the ideals of poor communities respecting health care

providers while health care professionals and organizations provide for community health care needs. I defined how communities respect, support, and collaborate with health care professionals and systems. In turn, I have given examples of how health care professionals provide for community needs, share resources, and represent the community to other health care and governmental organizations. Health care providers can lose respect when they seek to unfairly control the community, blame the community for its own problems, and subordinate community needs or desires to their own professional or personal needs. As respect is strengthened or increased, communities increasingly participate in health care planning, implementation, and evaluation.

The system of *machismo*, according to Mirandé and Enríquez (1979), was created and sustained in order to preserve a Latino family and social structure that could protect men and women from Spanish, and later, Euro-American, invasions or conquest. Similarly, I contend that *machismo*, as related to community identity and roles in health care systems, is sustained in order to provide community-based health care for its members. By engaging in respecting behaviors, both individually and collectively, the community ensures that health care will continue to be available for its members. From a position of relative powerlessness and economic insufficiency, practicing respect helps to encourage continued health care professionals' involvement in the community. This is not meant to imply that community *machismo* is the desired state, but that it is one way that poor communities adapt to otherwise negative societal forces, such as powerlessness and social class differences, to meet its needs. It is my theory that the more the community respects health care professionals and their organizations, supports health

care delivery, and collaborates with health care planning and implementation, the more the health care professional or system will provide for the community's health care needs, share health care resources, and represent the community to outside organizations in the context of Ecuadorian culture, poverty, and urban environments.

In the final chapter, I summarize the study, describe its limitations, review and discuss my findings on how participation occurs in poor urban Quito communities, and suggest ways that health care professionals can encourage community participation. Finally, I will suggest further research considerations for community participation and nursing practice in community.

CHAPTER 6

DISCUSSION AND CONCLUSIONS

To study community participation as a natural process and within a low-income urban setting, I chose three communities in Quito, Ecuador, and spent a year observing and interviewing community and professional participants. I spent three to four months intensively in each community collecting data, and continued to visit the communities occasionally throughout the analysis and writing processes to verify research findings. The first community, San Pablo, had a child's tutoring and health care project supported by a local hospital, an example of a non-governmental organization. Cabascango was the second community where I observed an example of a health subcenter, part of the Ministry of Public Health. The third community was a group of people who had formed a private foundation to provide AIDS care to patients and their families, another non-governmental organization.

Analysis began with the second interview and continued simultaneously with further data collection. Interviews, observations, and such corollary data as newspaper articles about health care or printed booklets from the Ministry of Public Health were first coded for major themes such as client and group participation and descriptions of regular health care activities. As new interviews and observations were added, codes were refined, added, and eliminated. For example, code words *cambios* (changes) and *vocación* (vocation) were set aside when more emphasis was placed on code words *comunidad* (community or group participation) and *mujer* (women). I wrote memos

beginning with the third or fourth observation, using memo writing as a way to flesh out ideas in the codes, and to search for links between codes.

STUDY LIMITATIONS

I analyzed the data from the perspective of the community as a group. For practical reasons, however, I examined only three communities. This limited sample size reduced the possibility of making comparisons between communities. Because I used *palanca* as a means of entry to the communities, the sample is a convenience sample based on my available contacts. There were other communities that I could have included in the study but I chose those to which I had access and that varied from each other.

Language is another potential limitation of the study. I conducted and transcribe all the interviews in the first language of the respondent, either Spanish or English, and I initially analyzed interviews in Spanish. I wrote my observational notes in English and eventually converted all codes and analysis to English as well. Therefore, the process of translation may have altered some meanings in the analysis. Because English is my first language, it would have been difficult to conduct the entire study in Spanish, especially writing up the results. Since the dissertation required English, it was more practical to write in English from the beginning. However, I discussed research findings in Spanish with Ecuadorian nursing colleagues, verifying language usage and ideas. There was constant discourse between Spanish and English. An ideal study team would have included both native Spanish and native English speaking researchers, but the doctoral

program required that I complete an original study on my own.

The lack of available literature in Spanish in Ecuador on community participation and other concepts related to the study limited my ability to consult local literature for analysis. Therefore, I used the resources in the University of California, San Francisco library, where the majority of existing literature on Latino culture was from the Mexican-American perspective. Therefore, I include this literature with caution. Additionally, the distance between my data collection sites and my research sponsor and other doctoral colleagues was a disadvantage. Although electronic mail is very useful, it was difficult to share large portions of my data or analysis process with colleagues.

Although I attempted to verify my results with community members, I felt that they were agreeing to anything I said to explain the process of community participation. I abandoned the notion of auditability of findings with research participants and instead utilized both Ecuadorian and American nurses and other professionals who were personal friends and colleagues to discuss my ideas of *machismo* in community terms. This was probably not ideal but the only available forum for auditing findings. Overall, I have developed a theory of respecting with a framework of *machismo* in community participation, a theory that is appropriate to the cultural, financial, and social context of the study.

OVERVIEW OF FINDINGS

A question that recurred during this study was, precisely what is a community? Although the study described three specific geographical locations in Quito, the

community was not the building, the neighborhood, or the clinic, but the people who inhabited those places. With its focus on the community as client or collective action, this study expands the community health nursing literature (Chalmers & Kristajanson, 1989; Dunn & Decker, 1990). Some community health nursing theorists describe a community as a system, but I find systems theory too mechanistic. A community is more like a one-celled amoeba, alive, in constant motion, with ever changing boundaries. People are constantly added to a community, other people leave. Some communities have more member interaction, others have less. Some communities share a strong sense of purpose, others a weaker or more informal purpose; some are more formally organized and others less.

I found that communities were formed by individual members of society joining together around a common concern or need. In Quito, some communities coalesced around housing needs -- called *barrios* (neighborhoods) -- while others joined together to solve mutual problems or for mutual interests -- like AIDS foundations, professional organizations, or religious assemblies. Community members participate in community events and activities, with each other and with members of other communities. Community members who choose not to participate may refrain, and may even choose to leave the community. In a relatively free society, such as Ecuador, individuals are not generally constrained from leaving or joining other communities, except in the case of prisons. In community *barrios*, activities are largely cooperative in nature and less formal in organizational style. Community leaders are frequently elected by a simple majority and counted on to meet regularly for the purpose of organizing such community services

as water, food, and health care, or for other activities of a social, political, or professional nature. Health care is one perceived area of community need, an arena in which community members participate with health care professionals and systems.

Health care professionals are infrequently members of the communities that they serve because of their different social position, financial resources, or educational achievements, which is certainly true of poor, urban, Quito communities. Rather, health care professionals view the community as their client in a business rather than a social relationship. As a business, health care is more competitive in nature, more formally organized, and contains a more complex hierarchical structure than a neighborhood community that is more informal or social in organization.

I found that there is a limited amount of community participation, as defined by the World Health Organization, in these poor, urban *Quiteño* communities (Oakley, 1989; WHO, 1978). The theoretical ideal of communities participating in health care planning, implementation, and evaluation is very limited in practice. The reasons include professionals' lack of will to share decision making power or authority, and the community's perceived lack of knowledge and personal resources. Nevertheless, participation does occur at individual and collective levels. In both San Pablo and Cabascango community members participate passively, by receiving health care personally or by carrying out decisions made by health care providers. Community representatives participate in planning meetings as consultants or committee members. Community autonomy is very limited. The Support Foundation takes a more self-care approach (Rifkin, 1981) by forming its own decision-making board of directors and

organizing its own health care for community members.

I categorized participation as interactions between community members that varied in intensity, frequency, and duration. Interactions took place most frequently between individual clients and health care professionals, but also between community and health care representatives, and between community representatives and representatives of other public and private organizations. I observed that more frequent, intense, or lengthy the face-to-face interactions between community members and health care personnel was associated with more CP in that setting. In San Pablo, the interactions were more frequent and of longer duration than the other two communities, prompting more community loyalty, support, and participation in health care. With the Support Foundation, interactions were more intense because of the weight of the issues around AIDS care. It was in Cabascango that interactions were fewer, shorter, and less intense, and where fewer community members volunteered to be involved in health care.

I also studied the role of volunteers, contrasting the paid positions of health care providers with unpaid positions for community volunteers. In this study, as in the existing literature on volunteerism in community health, the majority of volunteers are women. Men volunteer as community representatives and are frequently involved in formal meetings between the community and health care representatives, but are less often involved in the day to day operations of health care delivery. Because community members are frequently volunteers instead of paid participants, they have little influence in health care decisions, are sometimes resented by health care professionals, and are motivated by notions of the common good for the community rather than by personal

gain. There is great potential to exploit community volunteers and possible exploitation should be carefully considered when volunteers are used.

Analyzing the data theoretically, I found that communities respecting health care providers is a process by which poor, urban communities can encourage local health care availability and can have some degree of influence in community health care decisions given the imposed constraints of poverty, social stratification, and power imbalances. In this view, participation is an adaptive behavior. If the communities had more money, they could probably demand better health care but, being poor, they are required to ask for it and cooperate with those who have more power to make health care decisions. The community's goal is to make health care available for its members so it chooses to participate with health care systems. Even though some health care providers are richer than their clients, more powerful, act more controlling than cooperative, and even act abusively at times, community members continue to participate. It is often the community's only choice. If there were no ill community members, there would be no need to participate.

I have presented respecting and losing respect within a framework of *machismo*, a particular form of patriarchy in Ecuadorian culture. I am not supporting gender ideologies and cultural norms of behavior as they have been written about in Latin American culture. Rather, much as Del Castillo (1993) has written about covert gender roles, I am pointing out that Ecuador's cultural gender ideologies have been applied to groups of people, specifically to poor communities and rich health care professionals. As *machismo* may be viewed as a mechanism for the Latina family's survival, so respecting

is a mechanism by which poor communities survive in the health care environment. The community demonstrates respect by giving preference to health care professionals, following professional's decisions, verbally supporting existing health care delivery, and collaborating with time, money, and other physical resources. In return, the community expects that health care providers will provide health care on a regular and adequate basis, share physical resources, and represent the community to other organizations.

I theorize that communities give respect, a particular type of participation, in order to get health care. In other words, from the perspective of the community, more respect is given in exchange for more or better health care. When more health care is provided to community members, they participate more in health care plans and activities. What implications are there for professionals who may want to encourage or increase community participation with poor urban groups? I believe that respecting and providing can occur simultaneously. The more health care professionals and organizations provide for health care needs, share resources, and represent the community to others outside the community, the more the community respects those professionals and organizations. The greater the degree of respect, the more the community will participate, both individually and collectively, in health care planning and administration.

IMPLICATIONS FOR HEALTH CARE PROVIDERS

How can nursing and other health care professionals can encourage the maximum possible amount of participation? As evidenced in existing literature (Meleis, 1992; Rifkin, 1981), I found that health care providers exercised power and control over both

individual clients and community groups. As trained professionals serving poor populations, I observed many groups who desired professional leadership and decision-making. However, professionals' leadership can turn into authoritarianism where community autonomy is diminished rather than encouraged. This study demonstrates that, as much as possible, health care providers and planners must seek to provide for individual and collective needs within the community, share their personal and organizational resources with the community, and justly represent the community to other communities, organizations, and the government in order to elicit more participation. Contrarily, professionals should seek to limit the amount of coercion or control used with community members, to limit blaming the community for its problems, and to limit the times that community needs are subordinated to professional desires or needs. These activities require a greater degree of personal sacrifice and professional advocacy than I have seen demonstrated in this sample. Professionals who are unwilling to attend a Sunday afternoon community meeting, for example, are not willing to place the community good over their own. Likewise, professionals who do not seek out more health care resources for the community from local and international organizations are unlikely to be able to encourage participation.

When participation is not encouraged, professionals can also expect to be the recipients of undesired participation in the form of protests, loss of confidence, and loss of respect. Although loss of confidence and respect are highly intangible outcomes of participation, or lack of participation, they do influence the ability of the professional to do his or her job. If respect is sufficiently lost, professionals will ultimately lose their

influence within society. Replacing registered nurses with nurses' aides, replacing physicians with nurse practitioners or physician's assistants, replacing public health care with private enterprise are all the result, at least in part, of the failure of health care professionals to adequately meet the needs of societies.

The community's goal is the common good, and volunteers contribute time, money, and other personal resources so that the community has adequate health care services appropriate for its members. Meanwhile, among health care professionals, the most conspicuous interests are professional power and personal advancement. No one would deny that individual health care professionals have needs and desires which must be considered, nor would communities expect professionals to work without recompense. However, a basic failure in health care is the inability of health care professionals and systems to balance personal and collective needs.

Within Ecuadorian society, *machismo* allows for the man to be respected and have decision making authority, but requires a high degree of responsibility from the man in return for that respect. When the male fails to provide for the family's needs, he loses respect and he loses his privileges within the home. Likewise, I propose that health care professionals are respected within society as long as they provide adequate, appropriate, and affordable health care to members of that society. Health care professionals are respected to varying degrees within communities based on the degree to which they have met their professional obligations. If professionals wish to increase their influence within communities, they must ensure that they are providing for society's needs as much as for their own.

FURTHER RESEARCH

Nursing science would benefit from more studies of communities with analysis of group behavior in relation to nursing practice. For decades, nursing has concentrated on the individual client and has not adequately explored or defined the community level of nursing-client interaction. In studies of collectives, I believe that the community must be defined more specifically. Is a city or an entire cultural group a community, or are communities better defined as naturally occurring groups that have regular interaction around a common problem or concern? Public health nursing has, for years, defined the community as those who share a common disease or disease risk. Nursing science would benefit from expanding that definition to include a more sociological perspective of communities as naturally occurring collectives of individuals.

More studies are needed of communities that are not geographically located in neighborhoods or cities. For example, studying communities of faith, foundations and other non-profit communities, social groups, and sports clubs could contribute to nursing's knowledge of people in groups and their health care choices. Additional studies of community leaders or representatives and how they interact with health care systems are needed. How leaders represent the community and how health care providers respond to community representatives are still largely unexplored in health care.

There are many avenues of research in the area of community volunteerism as well. What motivates volunteers, what are the rewards of volunteering, what roles are best fulfilled by volunteers, and how volunteers and health care providers interact are all possible research topics.

There is still more research needed on community participation. What would participation look like if the community had more power or was not poor? It would be useful to compare participation between richer and poorer communities, between communities of predominantly different cultures, and between communities largely composed of women or of men. It may be helpful to conduct further critical studies of the power relationships between community members and representatives and health care representatives in situations of participation.

Lastly, notions of the common good as a community's goal need to be explored as they apply to nursing knowledge and practice. To what extent should individual community members contribute personal resources so that the community will have health care? How do we balance the needs of individual community members with the needs of the collective? There are ethical as well as practical considerations with reference to the ideas of personal versus collective good, individual and collective autonomy, for nursing practice. So that the nursing profession can know what services it can offer, and what services it should offer, nursing research must explore the meanings for the community and the larger society as the client.

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APPENDIX A - INFORMATION SHEET

UNIVERSIDAD DE CALIFORNIA SAN FRANCISCO INFORMACION DE UN ESTUDIO DE ENFERMERIA

PROYECTO: Participación comunitaria en Ecuador.

PROPUESTO: Lcda. Daniela Barnes, una estudiante post-grado en enfermería, y Dra. Juliene Lipson, una profesora de enfermería, ambas del Departamento de Salud Mental, Comunidad y Enfermería Administrativa, Escuela de Enfermería, Universidad de California San Francisco, están conduciendo un estudio para aprender el proceso de participación comunitaria con proyectos de salud en Ecuador.

PROCEDIMIENTOS: Si estoy de acuerdo colaborar en el estudio, me va a entrevistar por 30 a 60 minutos cuando y donde sea conveniente para mí. Durante la entrevista, me va a preguntar varias cosas sobre la participación de la comunidad en programas o proyectos de salud. Si estoy de acuerdo, se va a grabar la entrevista; si no, se tomará notas.

RIESGOS: Es posible que ciertas preguntas o temas serán incómodo para mí, o que no quisiera contestarlas. Tengo la libertad de no contestar una pregunta específica o terminar la entrevista a cualquier momento. Aunque la entrevista es confidencial, es posible que otras personas van a saber que he estado entrevistado. Para prevenir eso, va a guardar la cinta grabada y la entrevista escrita bajo llave y no van a comunicar mi nombre a otros. La entrevista será clasificado en código. Nadie va a saber mi identidad personal. Solamente las enfermeras en el estudio tendrán acceso a las cintas grabadas y los archivos. Cuando el estudio se haya terminado, las cintas serán destruidas. Los nombres verdaderos o la identidad de los participantes no serán utilizados en reportes ni en publicaciones que resulten de este estudio.

BENEFICIOS: Aunque no voy a recibir ningún beneficio directo, es posible que la información que doy puede ayudar a los profesionales de salud en el futuro en la administración de proyectos de salud.

COSTO: No será ningún costo directo para mí, más mi tiempo.

PAGO: Porque estoy dando mi tiempo personal, voy a recibir \$/. 10.000,00 (sucres) por la molestia. Seré pagado en efectivo inmediatamente después que completo la entrevista.

PREGUNTAS: Lcda. Daniela Barnes me ha explicado el estudio y ha contestado mis preguntas. Si tengo mas preguntas o comentarios sobre mi participación en el estudio, debo hablar con ella primero. Si por alguna razon no quiero hablar con ella, puedo hablar con alguien del Comite de Estudios Humanos, que esta involucrado en la protección de voluntarios en estudios. Puedo llamar a la oficina del comité entre 08h00 y 17h00, lunes a viernes, al número 011-1-415-476-1814; o puedo escribirle a la dirección:

Comité de Estudios Humanos
Box 0962
University of California, San Francisco
San Francisco, CA 94143
E.E.U.U.

Participación en el estudio es voluntario y estoy libre no estar en el estudio or salir del estudio a cualquier momento.

FECHA: FIRMA DE LA PERSONA QUE HACE LA ENTREVISTA:

[English translation]

**UNIVERSITY OF CALIFORNIA SAN FRANCISCO
INFORMATION ABOUT A NURSING STUDY**

PROJECT: Community participation in Ecuador

PURPOSE: Donelle Barnes, a doctoral nursing student, and Dr. Juliene Lipson, a nursing professor, both of the Department of Mental Health, Community and Administrative Nursing, School of Nursing, University of California San Francisco, are conducting a study to learn about the process of community participation with health projects in Ecuador.

PROCEDURES: If I agree to collaborate in the study, I will be interviewed for 30 to 60 minutes when and where it would be convenient for me. During the interview, I will be asked various things about the participation of the community in health programs and projects. If I agree, the interview will be tape-recorded; if not, notes will be taken.

RISKS: It is possible that certain questions or ideas will be uncomfortable for me, or that I won't want to answer them. I have the freedom to not answer a specific question or terminate the interview at any time. Although the interview is confidential, it is possible that other people will find out that I have been interviewed. To prevent that, the tape and written interview will be stored in a locked place and my name will not be mentioned to others. The interview notes will be given a code number. No one will know my personal identity. Only the nurses in the study will have access to the tape recordings and the files. When the study is finished, the tapes will be destroyed. The real names or identity of the participants will not be used in reports or publications that may result from the study.

BENEFITS: Although I will not receive any direct benefit from the study, it is possible that the information that I give can help health professionals in the future in the administration of health care projects.

COST: There will be no direct cost for me, except for my time.

REIMBURSEMENT: Because I am giving my personal time, I will receive \$/. 10,000 (sucres) for my trouble. I will be paid in cash immediately after the completed interview.

QUESTIONS: Donelle Barnes has explained the study to me and has answered my questions. If I have more questions or comments about participation in the study, I should first talk with her. If for some reason I don't want to talk with her, I may contact the Committee on Human Research, which is concerned with the protection of volunteers in research projects. I may reach the committee office between 08:00 and 17:00 hours, Monday through Friday, by calling 011-1-415-476-1814; or by writing:

Committee on Human Research
Box 0962
University of California, San Francisco
San Francisco, CA 94143
U.S.

Participation in the study is voluntary and I am free to not be in the study or leave the study at any time.

Date:

Signature of the interviewer:

APPENDIX B - INTERVIEW AND OBSERVATION GUIDES
GUIA DE ENTREVISTA

1. ¿Qué es su rol en la comunidad ____ [nombre de la comunidad]?
2. ¿Qué ha estado pasando con el proyecto de salud o sistema de salud que la comunidad está haciendo ahora? [Pregunta por la historia del proyecto o sistema de salud y las actividades corrientes.]
3. ¿Cómo piensa Ud. que los miembros de la comunidad están participando en el proyecto? Los líderes comunitarios?
4. ¿Cuál otro grupo o individuo está ayudando la comunidad en el proyecto de salud? [Pregunta por los profesionales de salud, oficios del Ministerio de Salud Pública, organizaciones no gubernales, iglesias o fundaciones, organizaciones internacionales como la O.S.M., y otros.]
5. ¿Cómo ayuda a la comunidad cada grupo o individuo?
6. ¿Qué hacen los grupos o individuos prevenir el avance del proyecto?
7. Si fuera su decisión, ¿qué quisiera Ud. que haga, o no haga, cada grupo o individuo ayudar el proyecto de salud seguir adelante?
8. Los datos demográficos:

Su edad

Sexo:

Su posición o puesto en la comunidad:

Número de años que Ud. ha vivido/trabajado en la comunidad:

Su trabajo o profesión:

INTERVIEW GUIDE

1. What is your role within the community ____ [name of community].
2. What has been happening with the health care project or health care system that the community is currently doing/involved with? [Probe for the history of the project or health care system as well as its current status.]
3. How do you think community members are participating in this project? Community leaders?
4. What other groups or individuals are helping the community in this project? [Probe for health care professionals, Ministry of Health officials, non-governmental organizations, churches or Foundations, international organizations such as W.H.O., etc.]
5. How does each group or individual help the community?
6. What do these groups or individuals do that prevent the project from moving forward?
7. If it was your decision, what would you like these groups and individuals to do, or stop doing, to help the health care project move forward?
8. Demographic data:

Age:

Gender:

Your position in the community:

Number of years that you have lived/worked in the community:

Your profession/job:

OBSERVATION GUIDE

1. Who is present at the meeting or event, including the number of people present and their gender, age, ethnic identity, position within the community, dress and any other information that would be relevant to what is happening in the group?
2. How is each person acting, both in speech and behavior? [Behavior would include any nonverbal gestures, and any rules of etiquette, legality, group policy, etc. that are demonstrated.]
3. How does each person enter into the interaction sequence?
4. How does each person relate to the others, as friend, colleague, subordinate, etc.?
5. What is the date, location, and time sequence of the interaction?
6. Describe the physical properties of the location where the interaction is taking place.
7. How is the researcher dressed, where is the researcher positioned in relation to the meeting or event, and how, when and why does the researcher enter the interaction?

OBSERVATION FORMAT

Date:

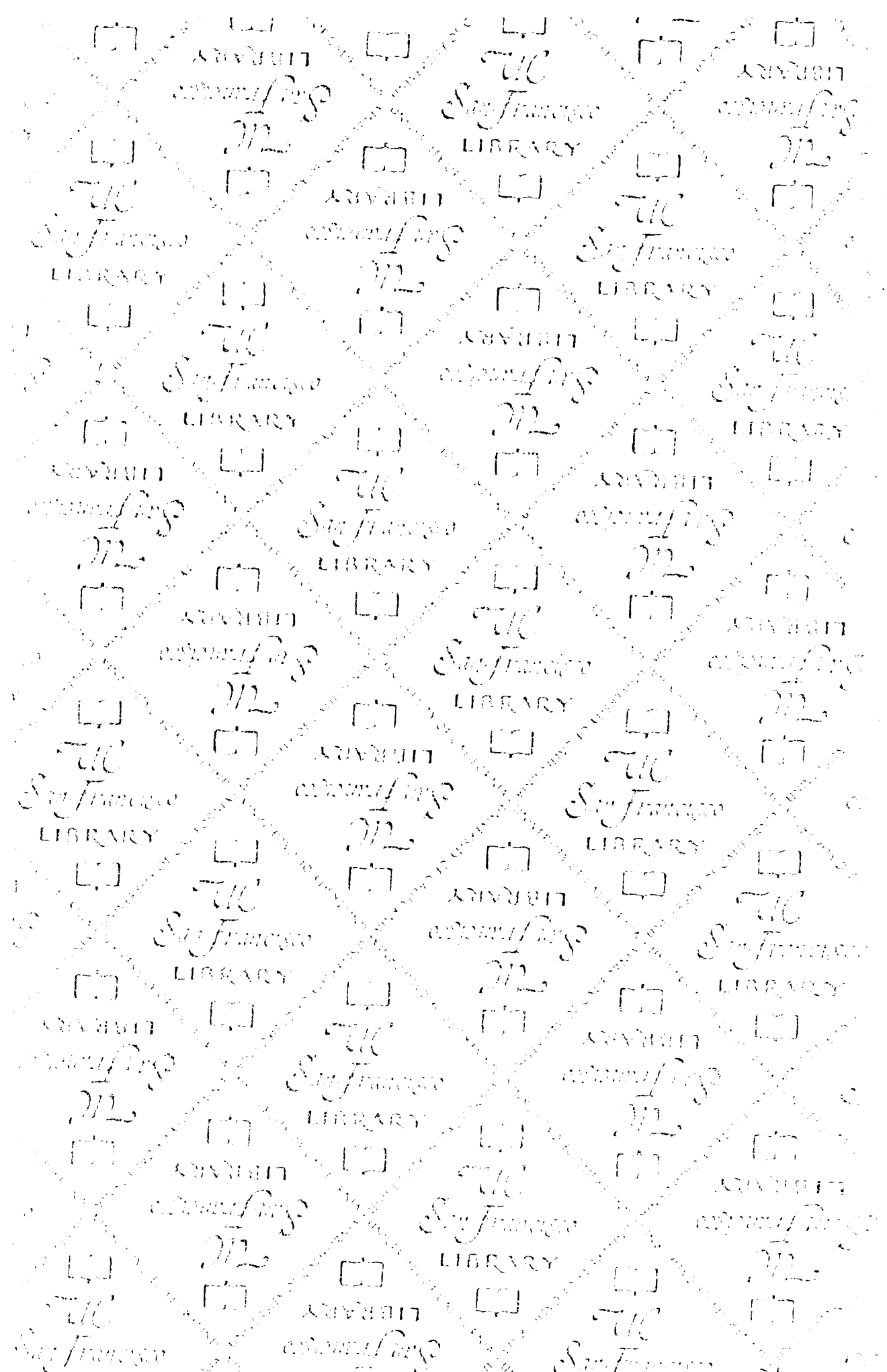
Time:

Location:

Observer's location, dress and interaction, if any:

List of participants [gender, age, position, dress, ethnicity]

Description of sequence of events, discussion and behavior:



For reference

Not to be taken from the room.

