EL CORAZON DE LA CEBOLLA: A MINI-ETHNOGRAPHIC STUDY OF MEXICANA/O SYMPTOM INTERPRETATION AND MANAGEMENT

by

Melody Weaver French

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SUPERVISORY COMMITTEE APPROVAL

of a dissertation submitted by

Melody Weaver French

This dissertation has been read by each member of the following supervisory committee and by majority vote has been found to be satisfactory.

Chair: Susan L. Beck

Lillian M. Nail

Muriel P. Shaul

1/1/2022
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Date

Susan L. Beck
Chair, Supervisory Committee

Approved for the Major Department

Chair/Dean

Approved for the Graduate Council

David S. Chapman
Dean of The Graduate School
ABSTRACT

The purpose of this urban mini-ethnographic qualitative study was to examine Mexicana/o symptom interpretation and management utilizing the Common Sense Model of Illness Representation as a guiding framework. Latina/os are a growing part of the population in the United States and are estimated to comprise 25% of the total population by the year 2050. The Latina/o population is diverse. Mexicana/os represent 68% of the Latina/o population in Utah.

Despite growing numbers of Latina/os living within the borders of the United States, little work has been conducted that addresses the healthcare needs of this population. Research to date has focused on issues of health status, utilization of health promotion and disease prevention services, barriers to healthcare, and explication of culture-based syndromes. In addition, little work has been performed to assess the interpretation and management of common symptoms.

Multiple methods of data collection were used, including meetings with key informants, interviews with participants, participant observations, photography, literature, documents, and artifacts. Immersion into the data and the development of a coding scheme were the initial steps in data analysis. Data management was accomplished with the assistance of QSR NUD*IST4®.

The Common Sense Model guided the research process. Participants told complex stories of symptom interpretation, with cost of healthcare emerging as the
overall theme affecting decisions regarding management of the symptoms they
selected. Although I initially believed that culture would play a much larger role in
how the participants addressed their symptoms, cost was an even greater issue.
Poverty may be a factor affecting healthcare and access to healthcare that is even
more important than culture. Further inquiry is warranted. However, clinical
practice will be enhanced through an understanding of the illness representation
and decision-making processes of the participants. Culture is an important factor
affecting specific ways in which participants address a particular symptom. What
may be considered by clinicians to be noncompliant behavior may be
implementation of self-care modalities prior to entering the conventional healthcare
system or following ineffective treatment by the conventional healthcare
system—decisions influenced by the cost of healthcare services.
To the people of La Raza who so graciously shared their stories.

Vayan con Dios mis amigos y amigas!
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PREFACE

This journey began when I was in elementary school. I walked to Rose's house after school each day to be greeted by the aroma of fresh tortillas, chili, and beans. I would listen as Rose and Abran spoke to each other in Spanish. One day I asked her if she was Mexican. Her response dripped with venom as she explained to me that she had been born and raised in New Mexico, which meant she was Spanish, not Mexican. I was confused by this explanation but too afraid to ask any more questions.

Later, as a nursing student at the county hospital in Los Angeles, most of my patients spoke Spanish and were in the United States illegally. As we discussed healthcare in my sociology class, I wondered why we (Anglos in the United States) had to spend so much money to take care of people who did not "belong" here. My thought was that they probably did not pay for their care. What a revelation I had when my research into this issue provided a totally different picture. The Mexican people, in this country illegally, all worked and did pay their bills for the care they received. It was the people (of all nationalities and color) who were born in this country who did not pay for their healthcare. From this experience, I developed a new-found respect for this hard-working group of people and made a concerted effort to communicate with them, at the very least in the healthcare arena.
Many years later I was working in a small rural hospital in central Texas. I introduced myself to Mr. Trujillo (tru-he-yo) and he began to cry. He told me that in the 30 years he had lived in this small town (mostly Anglos who had Mexicans working for them) no one had pronounced his name correctly until now. I was amazed that something as basic as someone's name could be taken from them. From that time on, whenever I encountered Spanish-speaking patients, I addressed them always by their names, trying to pronounce them correctly and asking them to teach me a new word in their language. This interaction went a long way in opening up communication inasmuch as both the patients and I were making the effort to speak with each other.

Eventually my journey led me to Utah. In Utah, I found a pervasive lack of tolerance and understanding of any person speaking Spanish who sought healthcare services in the emergency department where I worked. I often initiated conversations with my colleagues regarding their lack of tolerance towards this group of people who they perceived were “all the same” since they spoke Spanish. Many myths abounded: “They are all alike; they speak Spanish.” “They use the emergency room for all of their healthcare.” “They really don’t take care of themselves until they are very sick.” “They do not belong here.” I was sadly disappointed in my colleagues’ views of this particular group of people. Once again, I was confused as to how a group of professionals with caring at the very core of their paradigm for healthcare delivery could feel the way they did.
I had now come full circle. It was this journey that culminated in the research presented, research that focused on how a small group of persons of Mexican heritage described their journey into illness and the healthcare system in urban Utah.

Acknowledgments

It is difficult to take a journey of such great import without taking note of the many people who have provided sustenance along the way. I must first acknowledge Dr. Susan L. Beck, my dedicated chair, who patiently guided me through this process and made it seem an exciting adventure; Dr. Caren J. Frost who opened the doors of anthropology ever so slightly so that I could peer in and learn; Dr. Muriel P. Shaul who offered support and encouragement; Dr. Lillian M. Nail who offered insight and humor; and Dr. Theresa A. Martinez who graciously accepted this gringa into her beautiful world of La Raza.

I also must acknowledge Marlene Bacon and Gerrie Barnett for being there as moral support, lending their shoulders when tears were shed, laughing at all the mistakes made along the way, and simply being there in mind and spirit.

I acknowledge my husband, Mark, who gave his support and encouragement during this long process of growth, very little of which he understood, but he saw a light in my eyes as I told the stories and he vicariously felt the power of the experience. I also acknowledge my sons, Dillon and Sawyer, who were patient while mom sat at her computer for hours on end. I love you.
Finally, I acknowledge my parents for the last 46 years of love, support, and encouragement that helped me see that I could climb each hill and make it to the top of the mountain. I thank you.

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CHAPTER 1

INTRODUCTION

The face of this nation is changing. Although the majority of people residing within the borders of the United States are classified as White, ethnic minorities account for much of the population growth. Currently, 11.9% of the U.S. population is Latina/o (U.S. Bureau of the Census, 2000), but due to fluid movement across U.S. southern borders, this estimate may be low (Novello & Soto-Torres, 1993). By 2003, it is estimated that Latina/os will be the largest ethnic minority in the United States, surpassing Blacks. By 2010, approximately 13.5% of the U.S. population will be Latina/o, and by 2050, Latina/os will comprise 24.3% of the total U.S. population (U.S. Bureau of the Census, 2000). From 1990 to 1996, Utah experienced a 42% increase in its Latina/o population, making this group Utah’s largest ethnic minority (Foster, 1997) and accounting for 5% of the state’s population. The Latina/o population in the United States is primarily of Mexican origin, and Utah is no exception, with 68% of the Latina/o population being either Mexican American or Mexican national (Utah State Ethnic Office, 1995).

Although they are often looked upon as “new” additions to the population, Latina/os have been part of the fabric of this nation for a long time. Mexican Americans represent the largest proportion of Congressional Medal of Honor
winners of any ethnic group (Novello & Soto-Torres, 1993). This same source also noted the “strong” values of fervent patriotism, a strong work ethic, and loyalty to family held by Latina/os in this country. Novello and Soto-Torres stated:

Despite their many accomplishments, the crippling effects of poverty, lack of health insurance, unavailability of Spanish-speaking providers, and other persistent inequities continue to erode the health status of the Hispanic-Latino population—in particular, access to healthcare. (p. 529)

The Latina/o population is the most highly employed ethnic minority in America, most often in unskilled jobs that do not offer health insurance (Novello & Soto-Torres, 1993). This population is the least educated group, with only 52% completing high school (Novello & Soto-Torres, 1993). Latina/os are younger than the general population, with a mean age of 26.4 years (Aguirre-Molina & Molina, 1994). Many Latina/os living in the United States face language barriers. Other barriers also exist for Latina/os in accessing the healthcare system in this country such as a lack of health insurance, a lack of a regular healthcare provider, and possibly a lack of an understanding of the expectations for health promotion and disease prevention (Novello & Soto-Torres, 1993; Russeil & McCammon, 1995). Due to Medicaid ineligibility (based on legal residency), labor force characteristics, and family composition, Latina/os may be affected differently by healthcare policy initiatives (Valdez, Giachello, Rodriguez-Trias, Gomez, & De la Rocha, 1993); that is, they may not understand the process or simply may not qualify. The conclusion is that Latina/os remain “mostly” uninsured, which is one of the most frequently cited barriers to healthcare access.
Latina/os are less likely to seek healthcare within the conventional healthcare system until they are quite ill, often using emergency rooms for entry into the healthcare system for primary care problems (Council on Scientific Affairs, 1991). In addition, Latina/os are likely to use their own ethnomedical model of healthcare, relying heavily on self-care modalities such as traditional or folk remedies based on a Latina/o contextual understanding of illness. A lack of respect on the part of providers and a misunderstanding of the role of traditional remedies were mentioned most often as barriers to accessing the healthcare system in the most populated region of Utah (University of Utah Research and Evaluation Program, 1997). Therefore, it is imperative to understand ethnomedical models of healthcare and attempt to incorporate them into clinical practice.

While working in an emergency department in urban Utah, I had the following experience, which depicts the challenges faced by Latina/os and their healthcare providers:

Rosa came to the emergency department with abdominal pain. Her two sons accompanied her. Rosa spoke no English. Although I thought her sons would be able to translate [they spoke English], I did not want to embarrass Rosa by having her sons ask her questions about female problems. With the assistance of a translator, I found out that Rosa had similar symptoms 15 years ago. She went to the Matrona [healer for female problems] in her village. The Matrona put her hands inside her and “cured” her. Part of my examination included a pelvic exam. I tried to make it very clear that this was not intended as a “cure” for her abdominal pain. By the end of the encounter, it was clear that Rosa’s symptoms (thirst, hunger, frequent urination, and abdominal pain) were consistent with diabetes. Now began the task of assisting Rosa with learning about her diabetes and developing strategies for management that would be consistent with her worldview.
It was apparent that Rosa’s understanding of her illness (her interpretation and management) was culturally and contextually based. Had this information about Rosa’s previous experience not been elicited, she may have perceived the examination itself as a “cure” and again slipped through the cracks by not returning for follow-up care.

Another example of this incongruence occurred while I was working in a remote, rural practice setting. The resourcefulness and expertise that patients need to manage healthcare problems outside the conventional (biomedical model) healthcare system are apparent in the following story:

The medical assistant warned me before I entered the exam room, “It’s bad.” I was seeing Señor Torres for the first time. He had last been seen in the clinic 1 week before for second- and possibly third-degree burns to his right hand from a flaming gas-soaked rag. He was given emergency treatment and told to go to the burn center 2 hours away. He did not go. When I entered the room, I expected the worst. I found a very pleasant gentleman holding out his injured hand for my examination. I was struck by how good his hand looked. I asked him what he had been doing to take care of his injury. He described the meticulous care his wife had given him at home. They had purchased penicillin cream from the Botanica van that roamed the neighborhood with medicines from Mexico. His wife had cleaned his hand every day and applied the cream before a clean bandage. When I asked him why he had not gone to the burn center, he lifted his shirt and showed me a very large healed scar on his abdomen, stating, “Now this was bad, but my wife cleaned it every day and put the cream in and it healed. I knew she could take care of my hand.” I was impressed with their management of a rather severe injury. I wanted to monitor his progress, and he agreed to come back at intervals to let me check his hand. I never saw him again.

This encounter demonstrated a different paradigm in terms of utilization of the healthcare system. Señor Torres (or at least his wife) was adept at identifying
problems, managing the family's healthcare, and using multiple sources to solve them. This encounter seemed simply an opportunity for consultation regarding the treatment plan the couple had developed. In addition, this meeting served as an example of a pluralistic approach to solving a healthcare problem, whereas from a biomedical perspective Señor Torres's behavior may have been considered noncompliant.

Perceived patient noncompliance with a recommended healthcare regimen may be a lack of cultural competence on the part of the clinician. Was Señor Torres noncompliant? Was Señor Torres managing his healthcare in a manner that was culturally based from his own ethnomedical model of care? Charonko (1992) reported that when working with patients who are culturally diverse and of a culture different from the provider that it might be an issue of provider incompetence, not patient noncompliance. Germain (1992) stated:

Reconsideration of the notion of noncompliance with treatment is also in order. On closer examination, this label may be misplaced on the patient; noncompliance may result from failure on the part of providers to treat the patient's illness as well as the disease. (p. 9)

The concepts of illness and disease are different. Illness is the patient's perception of the experience with the change in his or her body, whereas disease is a well-defined term applied to a complex set of signs and symptoms and labeled by the medical establishment (Sargent & Johnson, 1996). Nurses tend to label a patient's concern about changes in bodily function as a symptom. In the present study, the term symptom is used to describe both illness and disease as presented by the participants. A more in-depth discussion of this illness and disease
dichotomy as well as symptoms appears in Chapter 2.

The healthcare system in the United States is driven by the biomedical model that may be foreign or often inaccessible to much of the Latina/o population. Latina/os perceive healthcare from a pluralistic viewpoint (Adams-McDarty, 1996; Ailinger & Causey, 1995; Barrett, 1995; Becker, Beyene, Newsom, & Rodgers, 1998; Cominsky, 1980; Koss, 1980; Parra, 1993; Russell & McCammon, 1995). Medical pluralism is defined as a system with many types of healthcare and healthcare providers, including shamans, healers, curanderas, midwives, bonesetters, herbalists, spiritists, and physicians (Baer, Singer, & Susser, 1997). Persons select who they see, when they see them, and what combination of healthcare modalities they believe best fit their needs. In reality, medical pluralism exists in this country (Leslie, 1980). However, the biomedical system remains dominant over other forms of healthcare (Baer, 1989), giving the appearance of a monolithic healthcare system. A lack of acknowledgment of medical pluralism in the United States contributes to issues regarding compliance and access to healthcare.

As mentioned earlier, much of the problem in clinical practice may be related to a lack of provider cultural competence. Campinha-Bacote (1991) defined cultural competence as a process in which the clinician or clinical agency "continuously strives to achieve the ability to effectively work within the cultural context of an individual, family, or community from a diverse cultural/ethnic background" (p. 1). The acknowledgment of medical pluralism as the manner in
which culturally and ethnically diverse persons may solve health and illness problems is a beginning step in developing cultural competence. Research examining the ways in which culturally diverse populations address health and illness is another way of solving health and illness problems. The present study contributes to this gap in the knowledge base.

**Problem Statement**

Many different terms have been used to describe the Latina/o population in the United States such as Hispanic, Chicano, La Raza, Mexican, and Latino (Marin & Marin, 1991; Molina & Aguirre-Molina, 1994; Ruiz-Contreras, 1995). The term Hispanic was coined by the U.S. Bureau of the Census as a way to try to classify the population of the United States by ethnicity. The terms Chicano and La Raza have sociopolitical origins, whereas Mexican often is used as a catchall term by persons who lack the knowledge of the diversity of this population. The term is applied to a particular group that stems from their identified country of origin such as Mexican Americans. Persons of Mexican heritage were the focus of the present study because of their predominance in the Latina/o population of Utah. For the purpose of this study, the term Mexicana/o was used to reflect the Mexican heritage of the study participants.

In the Mexicana/o community, la familia is an important concept (Caudle, 1993; Novello & Soto-Torres, 1993). Within the family structure, which can be extended, each member makes a contribution. Women are recognized as the primary caregivers during both health and illness (de Paula, Lagana, & Gonzalez-
Ramirez, 1996). However, due to the family-based focus of care rather than to the individual, this study was not limited to female participants.

In order to better serve a population, it is imperative to explore its common health problems and how individuals or families address them. Lau, Bernard, and Hartman (1989) suggested that understanding common illness experiences, since people have many more of those than serious illness episodes, will give clinicians insight into how people might interpret and manage a more serious health threat. Examining the ethnomedical model of healthcare incorporated into the daily lives of any given population serves to increase an understanding about how people address issues affecting their health status.

Although the number of Latina/os residing within the borders of the United States continues to grow, very little has been done to improve the health status of this ethnic minority (Molina & Aguirre-Molina, 1994; Novello & Soto-Torres, 1993). Much of the professional literature has focused on health promotion and disease prevention (Aguirre-Molina, Ramirez, & Ramirez, 1993; Marin & Marin, 1992; Skaer, Robison, Sclar, & Harding, 1996; Trevino, 1990; Zambrana, Scrimshaw, Collins, & Dunkel-Schetter, 1997) and folk medicine practices, giving special attention to specific culture-based syndromes such as empacho (blocked intestine), susto (taking a fright), and caída de mollera (sunken fontanelle) (Keegan, 1996; Marsh & Henges, 1988; Trotter, 1985). Little work has focused on common illness (Brown, 1980; Gordon, 1994; Mikhail, 1994). In fact, no work has focused on illnesses selected by the study participants. Much of the
research has focused on Mexicans of the southwest as well as regional studies of three specific Latina/o groups: (a) Mexicans, (b) Puerto Ricans, and (c) Cubans. Developing an understanding of illness representation and the management of illnesses selected by the participants from their emic (insider or native) perspective rather than a clinician's own ethnocentric medical model can serve only to enhance clinical practice.

Purpose of the Study and Research Questions

The purpose of this urban mini-ethnographic study was to examine illnesses selected by participants as well as their interpretation and management in a Mexicana/o population. Understanding these illness experiences may offer insight to clinicians regarding the interpretation and management of more serious health threats.

In exploring Mexicana/o illness experiences, I believed that it was important to ask the study participants what they were experiencing, what the experiences meant to them, and how they were managing the experiences. In order to gain as emic a perspective as possible, I addressed the following research questions:

1. What is the representation of the illness experience within the family unit?
2. How are these illnesses managed within the family unit?
3. Why are these illnesses managed in this way?
4. What are the patterns that emerge from within the study group regarding illness interpretation and management?

These research questions were explored using the ethnographic method. Ethnography is appropriate when (a) there is limited or no knowledge about a phenomenon, (b) the researcher wants to understand the phenomenon from the participants' perspectives, (c) the researcher is asking new or different types of questions, (d) the researcher obtains meanings in context, (e) the researcher generates new concepts or tests theories, (f) the researcher explores cross-cultural phenomenon, (g) the researcher identifies lifeway patterns of people, and (h) the researcher provides detailed accounts of participants' lives that are difficult to discover in any other way (Leininger, 1985). The emic point of view is explicated by the researcher, and the researcher's etic perspective (outsider or researcher) is used to explain that which is implicit to a particular culture. According to Leininger (1985), there are two types of ethnography: (a) mini-ethnography and (b) maxi-ethnography. These terms correspond to Fetterman's (1998) description of microlevel and macrolevel ethnography. Mini-ethnography is a "small scale ethnography focused on a specific or narrow area of inquiry" (Leininger, 1985, p. 35). This type of ethnography was selected due to the focused nature of the phenomenon of interest as well as to the limited time to conduct field work.

Theoretical Framework

The Common Sense Model of Illness Representation (hereafter referred to as the Common Sense Model) was selected as the theoretical framework to guide
the present study (Leventhal, Meyer, & Nerenz, 1980). Leventhal’s team of researchers applied the basic premise that illness is a subjective experience, whereas disease is an objective label usually applied by the medical establishment (conventional healthcare or biomedical model). The authors stated, “It is important to recognize we are articulating the patient’s logic, a logic which may be consistent and sensible even though its basic premises are completely invalid” (p. 16). This basic premise surmises that the researchers’ logic is valid, which is an inherent flaw in the development of this model.

Two basic assumptions provided the foundation for this model: (a) People are motivated to avoid and treat health threats, and (b) people are active problem solvers. The theory proposed that three basic sources of information help patients form their theory of illness: (a) bodily experiences, (b) environmental information, and (c) previous experience with the illness. Although the model has not been used in ethnically and culturally diverse populations, the use of process allows application of the model across varied populations. For the present study, the use of process provided a guiding framework within which the study phenomenon could be explicated.

Importance to Clinical Practice

Understanding illness representation from the emic perspective has great applicability to clinical practice. Most persons will attempt to manage their illness episodes prior to seeking more formal healthcare, but unless providers elicit this information, it remains an area of untapped resources and unknown knowledge
about how patients interpret and manage illness episodes. Germain (1992) stated:

Should popular and folk attempt at remedy fail, they are likely to remain private and hidden if the person seeks professional care. People are sensitive to the possible discounting of their cultural beliefs and practices that sometimes result from the ethnocentric bias of mainstream American healthcare—that our way is the best way and the only way. (p. 2)

Healthcare providers may have folk health beliefs that contribute to their own way of thinking about health and illness that in turn may influence their interactions with patients (Roberson, 1987).

Many terms have been used to describe this area of focus, including (a) cultural competence (American Academy of Nursing Expert Panel, 1992), (b) cultural relativism (Chrisman, 1996), (c) cultural care (Germain, 1992; Leininger, 1995), (d) culturally sensitive care (Caudle, 1993), and (e) intercultural medicine (Scott, 1997). The essence of all of these terms is a call for the provision of care that is culturally congruent with the patient’s voice regardless of the complexity of his or her own illness interpretation and management.

The American Academy of Nursing Expert Panel (1992) published a report to identify issues affecting the provision of care for culturally diverse populations with recommendations for research, education, and practice. Oncology nursing addressed cultural diversity and sensitivity in an entire issue of Innovations in Oncology Nursing (“Cultural Issues,” 1994) and has since published guidelines for cultural competence (Brant et al., 1999). The American Nurses Association (1991) published a position statement on the importance of cultural diversity to nursing practice. All of these nursing organizations have mandated the inclusion of cultural
competence as a goal for their organizations as they enter the 21st century.

Just as cultural competence has become a focus in nursing (Caudle, 1993; Lester, 1998a, 1998b), medicine also is calling for an understanding of intercultural medicine (Scott, 1997). Scott addressed physicians in the following statement:

Physicians diagnose and treat disease (i.e., abnormalities in structure/function of body system), but patients have symptoms and suffer illness (i.e., changes in body states). While physicians are thinking in terms of anatomy and physiology, their patients may be thinking in terms of yin and yang, thick or thin blood, or hot and cold. (p. 175)


Clinicians who work with culturally diverse populations must improve their ability to provide culturally competent care. One way to accomplish this type of care is to develop a better understanding about how people perceive illnesses and how they manage those illnesses. Bushy (1992) stated, "Incorporating self-care practices that are familiar to a client can result in nurses providing more effective, holistic primary healthcare to consumers" (p. 18). Self-care must be understood from the emic perspective and then integrated into the provision of care with patients. Clinicians must strive to expand their understanding of illness (emic perspective) in order to integrate this into the biomedical perspective (etic perspective) and to develop a more comprehensive plan for healthcare.
Keller, Ward, and Baumann (1989) stated, “First, careful descriptive studies of the representations of various illnesses should be done so that common sense ideas present in the culture can be documented” (p. 64) with the next step, making connections or links between these representations and coping strategies or symptom management. Therefore, the present research with a Mexicana/o population in an urban setting (a) focused on illnesses selected by participants as important to them and (b) explored the illness representation and its management. This study adds to the current body of knowledge regarding illness interpretation and management in an urban Mexicana/o population as well as giving voice to the participants' stories in clinical arenas, which creates an opportunity for increasing a clinician's ability to provide culturally competent care.
CHAPTER 2

REVIEW OF THE LITERATURE

The literature was reviewed to identify the current knowledge base regarding healthcare among Latina/os. The groundwork for this study was laid through an examination of demographics, Latina/o health status, healthcare services for Latina/os, acculturation, medical pluralism, folk medicine practices, symptom management, and illness representation. This review was an ongoing process that occurred throughout all phases of the study.

Several research strategies were used to conduct the literature review. The primary resource was computer databases. Numerous databases were searched, including Medline, CINAHL, and SocioFile dating from 1980 to the present. Key words included in the search were health, illness, Hispanic, Latino, health promotion and disease prevention, self-care, folk medicine, traditional medicine, symptom(s), symptom interpretation/management, medical pluralism, and Common Sense Model. The search was conducted beginning broadly with health and illness. The focus narrowed once the information was applied to Latina/os and Mexicana/os. A hand search of Index Medicus was conducted to include literature published prior to 1980. Other methods of literature acquisition included referrals from colleagues, bibliographies from presentations, and simply “paging through” every issue of especially pertinent journals available at a major university in the
intermountain west. References available through interlibrary loan were acquired as well. In addition, numerous books and other materials such as newspapers and television presentations were reviewed. The results of this literature review follow.

Demography

According to Delgado, Johnson, Roy, and Trevino (1990), the major Latina/o groups in the United States at the end of the 1980s were Mexican, Puerto Rican, and Cuban—all concentrated in the southwest, the New York area, and Dade County, Florida. Although these particular Latina/o groups remain large in these specific areas, the number of Latina/os residing in other areas is growing. Latina/os are primarily located in the following eight states: California, Florida, New York, Texas, New Mexico, Arizona, Colorado, and Illinois. Diversity within the Latina/o population also is changing. Although the major groups are Mexican, Cuban, and Puerto Rican, there has been an influx of persons originally from Central America and South America as well as islands in the Caribbean where Spanish is spoken.

Utah is experiencing this change in demographics as well. At the onset of the present study, the Latina/o population was estimated at 5.0% of the population of Utah (Utah State Ethnic Office, 1995), increasing to 9.0% by 2001 (U.S. Bureau of the Census, 2001). Some counties in the state have experienced as much as a 300% increase in their Latina/o populations. The Latina/o population of Utah represents multiple countries of origin, including persons of Mexican descent or origin as well as persons from Central America, South America, Puerto Rico,
Cuba, and other Caribbean islands. Many Latina/os speak Spanish as a first language.

As a group, Latina/os are younger (mean age 26.4 years), poorer, and less educated than their ethnic counterparts such as Blacks, Native Americans, and Asians in the United States (Aguirre-Molina & Molina, 1994). In 1993, the surgeon general’s report, entitled “T-O-D-O-S” (“Together Organized Diligently Offering Solidarity”), was the first national health initiative discussing the state of Latina/o health (Novello & Soto-Torres, 1993). It was noted that although two thirds of this ethnic group are citizens, 25% live in poverty. Latina/os are the most highly employed ethnic group in the United States, yet more than one third have no health insurance. Education is lacking, with only 52% of Latina/os completing high school. The Council on Scientific Affairs (1991) reported that Latina/os are at increased risk for diabetes, hypertension, tuberculosis, human immunodeficiency virus (HIV) infection, alcoholism, cirrhosis, certain cancers, and violent deaths. This group also reported that increased acculturation led to the adoption of numerous unhealthy lifestyle changes such as smoking. As the Latina/o population grows in the United States, it becomes more and more important to assess the health status of this group in order to set goals for improvement.

**Health Profile**

The only major examination of the health status of Latina/os to date has been the Hispanic Health and Nutrition Examination Survey (HHANES), which is a collection of data gathered from 1982 to 1984 by the National Center for Health
Statistics. These data focused on the Mexican population in the southwest United States, the Puerto Rican population residing in the greater New York area, and the Cuban population living in Dade County, Florida.

In a supplemental report (Trevino, 1990), multiple studies using the HHANES data set were discussed. Methodological issues involved the complex sample design, nonresponse bias, potential noncoverage bias, and the regional nature of data collection (Delgado et al., 1990).

Barriers to accessing and receiving care (Estrada, Trevino, & Ray, 1990; Solis, Marks, Garcia, & Shelton, 1990) and issues reflecting poor dietary habits, smoking, and utilization of services (Marks, Garcia, & Solis, 1990) were reported. The use of alcohol (Markides, Ray, Stroup-Benham, & Trevino, 1990), poor dental health (Ismail & Szpunar, 1990), and generational differences in perinatal health (Guendelman, Gould, Hudes, & Eskenazi, 1990) were reported as well. One portion of the study (Higginbotham, Trevino, & Ray, 1990) inquired about the use of curanderos in the southwest United States, reflecting a much broader use than was expected. Acculturation is a measure frequently used for correlations with many of the health factors examined.

Findings from the studies based on the HHANES data set documented many factors of Latina/o health, reflecting overall poor health for these populations of Latina/os. However, in terms of negative lifestyle changes such as smoking and drinking among women, there was a positive relationship between length of time in the United States and adoption of these behaviors, suggesting a loss of cultural
“protection” against these changes. Although measures of acculturation, an examination of barriers to access, and use of traditional healers were included, the healthcare issues were taken from an American ethnocentric perspective. The HHANES survey was the first major study of Latina/o health in the United States. However, the survey examined only Latina/o health from a U.S. health perspective as well as from a health promotion and disease prevention perspective. Although the Latina/o population has continued to grow, no other major national work has been conducted since that time.

In 1994, Molina and Aguirre-Molina edited a text entitled *Latino Health in the U.S.: A Growing Challenge*. These editors gathered together many experts on Latina/o health, with each chapter serving as a review of the work to date and addressing issues of Latina/o healthcare, access to healthcare, barriers to healthcare, chronic healthcare issues, and the general status of Latina/o healthcare in the United States. Carter-Pokras (1994) discussed the health profile of Latina/os in general and as specific subgroups. The profile included an overview of Latina/o healthcare based on the “current” information with regard to Latina/o healthcare.

Carter-Pokras referred to the HHANES data:

> Researchers should ensure that they go beyond describing the discrepancies in health status between Latinos and non-Latinos. Cultural aspects that provide some protection against the effects of poverty, low educational status, and low use of health services should be defined and encouraged. (p. 73)

Emphasis in this report was placed on obtaining knowledge of the Latina/o population in terms of acculturation, social class, and social isolation in order to
determine the best types of intervention for this population.

Both of these works described the poor health status of Latina/os and their underutilization of healthcare services (Carter-Pokras, 1994; Molina & Aguirre-Molina, 1994). Acculturation was identified as a factor that influences perinatal outcomes such as leading to fewer miscarriages; it was surmised that some facet of retained culture was protective against miscarriage. More acculturation was related to increased substance abuse; it also was surmised that there was increased exposure and acceptance of substance abuse as one becomes more acculturated. With their inherent ethnocentric flaws, these two works were based on the HHANES data set.

**Health Promotion and Disease Prevention**

The trend in the United States is to focus on health promotion and disease prevention. In studies examining health promotion and disease prevention, specifically in Latina/o populations, many issues lend themselves to creating a portrait of underutilization. Not having access to a regular source of primary care in which health promotion and disease prevention are often a central part of healthcare delivery may limit this population’s participation in these services (Aguirre-Molina et al., 1993). Focusing on problems that may not be of specific concern to this population such as heart attacks, strokes, hypertension, and certain types of cancer rather than major health issues that impact Latina/os such as motor vehicle accidents, maternal mortality, and cirrhosis (Hayes-Bautista, Baezconde-Barbanati, Schink, & Hayes-Bautista, 1994) may pose a barrier to utilization of
health promotion and disease prevention activities. One area of focus for health promotion and disease prevention is cancer. With regard to cancer prevention, it has been suggested that insufficient knowledge such as misconceptions about screening, cost, lack of trust with the system, and a degree of fatalism account for much of the decreased usage of health promotion and disease prevention services by Latina/os (N. Mortensen, personal communication, August 7, 1998; Perez-Stable, Sabogal, Otero-Sabogal, Hiatt, & McPhee, 1992; Skaer et al., 1996).

Concept of Health and Chronic Illness

Examining how Latina/os define the concept of health provides insight into the lives of elderly Latina/os, a group that is most likely to suffer from chronic illness (Adams-McDarty, 1996; Ailinger & Causey, 1995). An examination of the knowledge of chronic healthcare conditions (Becker et al., 1998) and perceptions of health (Shetterly, Baxter, Mason, & Hamman, 1996) suggests an implicit cultural variability in elderly people's overall state of health and management of their healthcare. These authors suggested that good health often is defined as simply being able to get out of bed or do one's chores. This perception of health may be incongruent with the perception of health promoted in the United States. In the view of some Latina/os, simply being diagnosed with a chronic illness such as diabetes or hypertension does not make one unhealthy. This paradigm may be a concept foreign to healthcare providers in the United States.

In summary, although Latina/os have been a part of the fabric of the United States for a long time, little has been done to alter the health status of this group.
Latina/os are relatively young, uneducated, and continue to work in jobs that do not offer health insurance. Latina/os are part of the working poor who keep the country operating. Sociocultural barriers such as fatalism and perceptions about health promotion and disease prevention and chronic illness also have influenced Latina/o health. Findings have suggested that the current focus of health promotion and disease prevention in the United States may not be targeting problems important to the Latina/o population.

**Health Services for Latina/os**

How to provide healthcare services to the Latina/o population remains a challenge. The aforementioned reports and studies addressed the broad issue of Latina/o health, health promotion and disease prevention, and perceptions of health.

Barriers to obtaining services for the Latina/o population have been examined in numerous studies. Equity and access to healthcare have been discussed in their broadest sense (Vladeck, 1981), whereas poverty, the cost of healthcare (Russell & McCammon, 1995), and the perceived mistreatment by healthcare providers (O’Brien et al., 1997) were more specific issues creating barriers to healthcare. Language and cultural differences (Russell & McCammon, 1995; Seijo, Gomez, & Freidenberg, 1991), compounded by a lack of bilingual providers and educational material (University of Utah Research and Evaluation Program, 1997; Valdez et al., 1993) as well as inadequate or no health insurance (Valdez et al., 1993; Valdez, Morgenstern et al., 1993) also have been identified as barriers to
accessing services for the Latina/o population. While these studies examined barriers to care for adults, inquiries focusing on children have revealed a mixed picture with regard to access. In an evidence-based review of articles specifically addressing barriers to care for Latina/o children, Flores and Vega (1998) identified barriers similar to adults, whereas a study of access to school-based care in Galveston, Texas (Gilman & Bruhn, 1981) revealed no differences in terms of access to, or use of, care among children regardless of ethnicity or acculturation.

Access to care is influenced by many barriers that affect persons seeking healthcare services. The Latina/o population is especially vulnerable due to a lack of health insurance, a lack of education, language issues, poverty, and cultural differences between themselves and providers within the conventional healthcare system. Consequences of these barriers can be devastating, as a study of injuries in Latino gardeners revealed (Glazner, 1995). These Latino gardeners often did not seek treatment regardless of the severity of the injury. Consequences included wound infections, loss of a limb, and loss of the ability to work. When questioned, they identified a lack of understanding of how the healthcare system worked for them.

**Acculturation**

One issue, which appears repeatedly in the literature with regard to Latina/o health, is acculturation and its influence on the utilization of services and health-related behaviors. Many of the previously mentioned studies measured acculturation as a covariate to utilization and health-related behaviors. The
importance of acculturation as a variable when conducting research with Latina/o populations has been cited by many authors (Dana, 1996; Marin & Marin, 1991; Molina, Zambrana, & Aguirre-Molina, 1994; Negy & Woods, 1992). Two issues are important with regard to acculturation. The first issue is a lack of a standardized definition for acculturation. The definitions range from those describing an adoption of certain aspects of a new culture to those that describe people as becoming of the new culture and leaving their native culture behind. The second issue is the question of whether or not it is acculturation or assimilation that is being measured, which is the primary issue in discussions regarding the measurement of acculturation. As previously stated, the definition of acculturation is not standardized. Many definitions include what some researchers believe are more clearly assimilation: the becoming of a new culture and abandoning one’s native culture.

Dana (1996) defined acculturation as “the process of adaptation or assimilation by an ethnic or racial group to a host culture and [it] can occur in sedentary or migrant individuals, not only voluntarily among immigrants, but involuntarily among indigenous peoples and refugees” (pp. 317-318). This definition is an example of the ambiguous nature of describing acculturation. Even with the apparent ambiguity and the argument by some Latino leaders that acculturation should not be measured, the measurement of acculturation is a hallmark of Latina/o research.
Many studies, in addition to the HHANES study, have examined acculturation. The relationship of acculturation to values (Domino & Acosta, 1987), pap smears and mammograms (Suarez, 1994), perinatal health (Fracasso, Busch-Rossnagel, & Fisher, 1994; Zambrana et al., 1997), condom use (Marin & Marin, 1992), sexual behaviors and attitudes (Marin, Tschan, Gomez, & Kegeles, 1993; Sabogal, Perez-Stable, Otero-Sabogal, & Hiatt, 1995), HIV and acquired immunodeficiency syndrome (AIDS) (Marin & Marin, 1990; Mikawa et al., 1992), alcohol (Cherpitel, 1992; Marin, Posner, & Kinyon, 1993), and illicit drug use (Wagner-Echeagaray, Schutz, Chilecoat, & Anthony, 1994) has been reported.

When related to values, the findings of acculturation are mixed. A positive correlation was found between acculturation and drinking, driving, and using illicit drugs. A negative correlation was found between acculturation and health promotion and disease prevention. However, acculturation was found not to influence maternal attachment or Mexicano values about life. Many of these studies suggested that being “more” acculturated meant being “more” like an American in terms of how one interacts within the dominant cultural milieu.

**Acculturation Measures**

Numerous methods have been devised to measure acculturation (Burnam, Hough, Telles, Karno, & Escobar, 1987; Deyo, Diehl, Hazuda, & Stern, 1985; Fracasso et al., 1994; Wagner-Echeagaray et al., 1994). Only the two most frequently cited instruments are discussed in detail.
In a psychiatric hospital in Texas, Cuellar, Harris, and Jasso (1980) developed an instrument, the Acculturation Rating Scale for Mexican Americans (ARSMA), using psychotic Latina/o patients, students, and staff (n = 222). Although the researchers did not define acculturation, their goal was to design an instrument that could be used by Mexican Americans from all socioeconomic and educational backgrounds regardless of preferred language (as long as it was English or Spanish). The instrument is a 20-item questionnaire (written or interview format) that can be used individually or with a group. The researchers reported an alpha coefficient of >. 80. Validity testing was addressed using numerous methods, including cross-cultural variation, generational differences, English/Spanish scores, and concurrent validity and factor analysis. The ARSMA can differentiate between groups and within groups as well as across generations and language differences. The ARSMA was developed for Mexican Americans only. This instrument has been used in numerous other studies (Domino & Acosta, 1987; Mikawa et al., 1992; Zambrana et al., 1997) as well as the HHANES study previously discussed. The ARSMA has been revised once. The ARSMA-II (Cuellar, Arnold, & Maldonado, 1995) is a 30-item, multidimensional instrument. Factors are assessed separately, attempting to measure four modes of acculturation: (a) integration, (b) assimilation, (c) separation, and (d) marginalization.

The second instrument, Short Acculturation Scale for Hispanics (SASH), was developed by Marin and colleagues (1987). Most of the developmental work for this instrument was conducted in the San Francisco area with Mexican
Americans and, more recently, with Central Americans. The SASH was developed as a 12-item scale with three factors: (a) language use, (b) media, and (c) ethnic social relations. The sample included 363 Latina/os and 228 non-Latina/o Whites. The scale differentiated between Latina/o and non-Latina/o Whites, with the three factors accounting for 67.6% of the variance. Language use was measured by five questions, and it alone accounted for 54.5% of the variance. The researchers suggested using the first five questions of the scale to measure acculturation.

Barona and Miller (1994) adapted the SASH for use in a group of fifth- through eighth-grade students in the southwest. The researchers differentiated between more and less acculturated students. Marin and Marin (1991) suggested using only four questions from the SASH. Norris, Ford, and Bova (1996), in their study in Detroit, Michigan, with Latina/o adolescents and young adults, used only four questions from the SASH. They found the SASH to be an acceptable measure for the acculturation variable. This instrument is discussed in more detail in Chapter 3.

Acculturation is not a well-defined concept, but its influence may be useful for exploring health and illness behaviors. Acculturation may affect how the healthcare system in the United States is viewed and utilized.

**Medical Pluralism**

Healthcare in the United States is driven by the biomedical model, a model that focuses on curing disease, with treatments and technology based on the scientific process and with emphasis on individualistic behavior. In a discussion of healthcare in the United States, Leslie (1980) stated:
The generic conception of a medical system is thus based on a single, historically recent system: a bureaucratically ordered set of schools, hospitals, clinics, professional associations, companies, and regulatory agencies that train practitioners and maintain facilities to conduct biomedical research, to prevent or cure illness, and to care for or rehabilitate the chronically ill. (p. 191)

Although biomedicine holds a dominant position in the healthcare arena in the United States (Baer, 1989), healthcare consumers continue to address their healthcare issues from a pluralistic paradigm. In the United States, this pluralism takes the form of (a) conventional medicine (the formal system of healthcare with physicians, hospitals, and clinics [biomedical model]); (b) alternative therapy (those modalities "outside" conventional medicine); (c) complementary medicine (those modalities recognized by conventional medicine as being adjunctive); and (d) folk medicine (usually culture-based modalities). This discussion is not meant to be a presentation of medical pluralism as it exists in the United States but rather as an introduction of the concept itself with examples pertinent to the Latina/o population.

In studies focusing on Latina/os in Guatemala (Cominsky, 1980), Puerto Rico (Koss, 1980), Mexico (Parra, 1993), and Nicaragua (Barrett, 1995), the use of medical pluralism was reported. From the finca (plantation) in Guatemala to rural Mexico and Nicaragua as well as the institutions of Puerto Rico, the use of multiple sources for addressing healthcare needs was evident. Conventional providers and spiritists in Puerto Rico came together to offer collaborative services. Problems with unsafe practices were identified and addressed in Guatemala. The governments of Mexico and Nicaragua had varying degrees of
success incorporating traditional healers into conventional health systems.

On the surface, healthcare in the United States appears to be monolithic, but there is a trend towards medical pluralism. As time passes, the existence and acknowledgment of medical pluralism in patient care will create an environment where self-care measures, including folk medicine practices, will be seen as integral parts of seeking solutions to illnesses and of maintaining health.

**Self-care**

The literature is abundant with references to self-care. Gantz (1990) reviewed perspectives of self-care from six disciplines, including medicine, nursing, psychology, health education, public health, and sociology. It is apparent that within and across disciplines there is no universally accepted definition of self-care. Each of the disciplines focused on self-care from a discipline-specific perspective, with none agreeing on a single definition. The definition of nursing focuses on improving health status, coping, and functioning.

Within nursing, Bushy (1992) discussed self-care and its relationship to folk medicine, defining self-care “as the practices a lay person uses on his or her own behalf in health promotion, disease prevention, and in disease detection and treatment” (p. 10). The discussion focused on folk medicine as one part of self-care practice. Three categories were identified: (a) treatment of short-term conditions, (b) treatment of chronic and incurable conditions, and (c) treatment of psychosomatic conditions (Bushy, 1996). Bushy stated that there must be a willingness on the part of healthcare professionals to understand that self-care
modalities at times may be more effective than conventional healthcare practices and that the practice of these modalities must be acknowledged. Bushy supported the need for a collaborative nurse-client relationship, recognizing the importance of the client's ability to perform self-care measures. Valuing a patient's use of these self-care modalities may create an environment where patients feel comfortable divulging their use and, thus, decrease the incidence of inappropriate or duplicate treatments. Wykle and Haug (1993) went even further in their discussion of self-care practices in older persons from different backgrounds (e.g., Anglo, African American, and Latina/o), suggesting that the use of self-care practices may decrease healthcare expenditures. In contrast, Hufford (1997) discussed the need for healthcare providers to learn "tolerance" of folk medicine practices, learning how to "deal with" folk medicine in the clinic.

Use of Folk Medicine

The use of folk medicine by Latina/os has been the focus of many studies. Case study presentations (Krajewski-Jaime, 1991) as well as clinic-based studies conducted in the southwest United States have focused on the uses of folk medicine by different ethnic groups (Becerra & Iglehart, 1995). Mexican Americans in the Texas Rio Grande Valley reported using alternative therapy, but not all of them reported this use to primary care providers (Keegan, 1996). Each of these studies described the use of folk medicine as study participants incorporated its use into their overall healthcare, validating the pluralistic approach that is commonly used.
Much of the focus of study with regard to the use of folk medicine in Latina/os has centered on culture-based syndromes (Marsh & Hentges, 1988; Trotter, 1985) such as *empacho* (blocked intestine), *susto* (taking a fright), *mal de ojo* (evil eye), and *caida de mollera* (sunken fontanelle). The results of these studies have demonstrated that the belief in and the use of folk medicines for culturally bound syndromes are not socioeconomically based. Although inappropriate treatment of *caida de mollera* could endanger the life of the infant, most treatments of these maladies were not harmful.

In summary, the Latina/o people use home remedies and folk medicine to address their healthcare needs. Persons of all socioeconomic levels use these practices to some degree. Fearing disapproval, it is clear that they do not tell their primary care providers. Research has focused on culture-based syndromes, highlighting differences between conventional healthcare and traditional healthcare beliefs and practices, rather than on more common illness experiences.

**Illness and Disease Dichotomy**

As previously mentioned, a dichotomy between illness and disease exists. In the field of medical anthropology, this area is of particular focus. Much of the discussion focuses on the differences between the patient and the clinician in terms of how illness and disease are perceived. At times, both the patient and the clinician use premises that are in direct opposition to one another. Disease is considered the "doctor's" perspective, whereas illness is considered the "patient's" perspective. Helman (1994) defined disease (from a medical perspective) as "a
deviation from these normal values, accompanied by abnormalities in the structure
or function of body organs and systems” (p. 103). He defined illness as

the subjective response of an individual, and of those around him, to
his being unwell; particularly how he, and they, interpret the origin
and significance of this event; how it affects his behavior and his
relationship with other people; and the various steps he takes to
remedy the situation. It not only includes his experience of ill health
but also the meaning [author’s emphasis] he gives to that experience.
(p. 107)

The medical definition of disease assumes that there is a universality to the form,
progress, and content of a particular disease without considering the individual
patient’s or his or her family member’s response to the change in bodily function
or the context within which this occurs. Illness is part of a wider conceptual model
that is influenced by the psychological, moral, and social dimensions of culture.

This dichotomy between disease and illness also is reflected in differences between
medicine and nursing. Medicine approaches the patient from a disease perspective,
whereas nursing approaches the patient from an illness perspective. In nursing, the
term symptom often is used to represent the manifestations of illness.

**Symptoms and Symptom Management**

Most instances of folk medicine or other types of healthcare use were
initiated based on the occurrence of a symptom, a change in the body. In nursing,
this subjective cue is referred to as a symptom that the person is not well.
Understanding symptoms and symptom management is important to understanding
why and how a person cares for himself or herself or family members.
The work of Rhodes and colleagues has focused on symptom distress, which they defined as “the need to alter (restrain or produce) actions in response to a subjective indication of disease or illness” (Rhodes & Watson, 1987, p. 243). In a 1987 issue of Seminars in Oncology Nursing, symptom distress was presented as a concept (Rhodes & Watson, 1987) as well as a focus of future research (Watson, Rhodes, & Germino, 1987). Issues regarding theoretical frameworks on which to base this work as well as how to measure symptom distress were discussed. This trend appeared to be the beginning of a focus on symptom management for nursing. The emphasis on symptoms as the patient’s experience with and of a phenomenon separate from the disease or diagnosis has proved to be a fertile area for nursing practice, investigation, and research.

Symptom is defined as “a sign or indication of something” (Barnes & Noble Books, 1996, p. 1927). Rhodes and McDaniel (1996) defined symptom as “unique” and “not observable.” Their definition of symptom was further developed as follows:

They can be perceived and verified only by the person experiencing the event; they cannot be observed, perceived, or verified by other persons. Symptoms may or may not be related specifically to a medical problem and may have a strong psychosocial element. They may be either continuous or intermittent. Regardless of the occurrence of a symptom, the distress from a symptom may escalate over time. Therefore, the symptom experience affects patients’ self-care and coping abilities and their quality of life. (p. 3)

For the purpose of this study, it was assumed that symptoms were the primary subjective representation of illness and that the terms were used interchangeably.

Since some problems such as a fever are both subjective and observable, I did not
differentiate between a sign or a symptom.

Models

An overview of four symptom management models is presented in Table 1. Illness representations or symptom experiences are the phenomena central to each model. The Common Sense Model (Leventhal et al., 1980) served as the template from which each of the other models evolved.

Each of these models (see Table 1) demonstrates the process of symptom interpretation and management examining input, assessment, and outcomes. The initial Common Sense Model of Illness Representation does not address the issue of culture. However, the model is simplistic in its description of the process of illness representation and allows for the addition of other factors that may influence illness representation. The Symptom Management Model includes culture as a variable (University of California, San Francisco School of Nursing, 1994); the Symptom Interpretation Model mentions culture as a consideration (Teel, Meek, McNamara, & Watson, 1997); and the Symptom Self-care Response Model uses persons of varied ethnicity, making culture implicit to the illness representation process (Sorofman, Tripp-Reimer, Lauer, & Martin, 1990). However, all of these models fall short of applicability for an exploratory study into symptom interpretation and management in populations that have been understudied due to their complexity.
Table 1

*Symptom Interpretation Models: A Comparison of Four Models*

<table>
<thead>
<tr>
<th>Model</th>
<th>Representation</th>
<th>Coping</th>
<th>Appraisal</th>
</tr>
</thead>
<tbody>
<tr>
<td>Common Sense Model (Leventhal, Meyer, &amp; Nerenz, 1980)</td>
<td>Identity, Cause, Time line, Controllability, Consequences</td>
<td>Cognitive*, Emotional*</td>
<td>Cognitive*, Emotional*</td>
</tr>
<tr>
<td>Symptom Interpretation Model (Teel, Meek, McNamara, &amp; Watson, 1997)</td>
<td>Input, Environmental disturbance → awareness</td>
<td>Interpretation, Recognition, Categorization, Evaluation</td>
<td>Outcome, Action versus no action</td>
</tr>
<tr>
<td>Symptom Self-care Response Model (Sorofman, Tripp-Reimer, Lauer, &amp; Martin, 1990)</td>
<td>Symptom recognition</td>
<td>Symptom evaluation, consultation, and implementation</td>
<td>Symptom outcomes</td>
</tr>
</tbody>
</table>

*Used to signify that the representation stage of the Common Sense Model has both a cognitive and an emotional experience.
Culture

The role of culture in relationship to symptoms as well as to their meaning and interpretation has not been widely presented in literature originating in the United States. Wenger (1993) discussed the cultural meaning of symptoms. She defined symptoms "as phenomena experienced by individuals that signify a departure from normal function, sensation or appearance, physical aberrations, or, even more personally, as "that most private of sensations"" (p. 22). Wenger defined culture as "the learned, shared, and transmitted values, beliefs, and practices of a particular group that guide thinking and actions in patterned ways" (pp. 22-23).

In a review of nursing literature, Wenger (1993) noted that culture rarely was included as important to symptom interpretation. She discussed the understanding of cultural meanings as they relate to symptoms as a translation process. This process has been described as bidirectional and involves experience of the symptom by the client that leads to analysis within a cultural context. From a cultural perspective, this information is shared with the clinician or researcher and is restructured within the receptor. Inherent assumptions in this process are (a) that the clinician or researcher believes that people know and can articulate their knowledge, values, and beliefs; (b) that the researcher or clinician assumes the learner role in the interaction; (c) that semantic and linguistic terms may be specific to the culture; (d) that judgment is suspended; (e) that the client is given opportunity to reflect; and (f) that negotiation is between the client and the
researcher or clinician. Wenger demonstrated this process by sharing case studies from her work with Soviet Jewish immigrants and the Amish. This body of work is grounded by Leininger’s (1991) Cultural Care Diversity and Universality Theory and Kleinman’s (1980) use of explanatory models. Wenger demonstrated a gap in the knowledge base of nursing with regard to cultural context of symptom interpretation and management.

Illness Representation

Illness representation is not new. In research conducted in China, Kleinman (1980), a psychiatrist and anthropologist, presented illness representation using an explanatory model. His format for eliciting an illness included the following questions: How did it start? What do you call it? What do you think caused it? How long did you think it would last? What did you do about it? These five areas of inquiry serve as a template for the five areas of representation in the Common Sense Model.

How one perceives a symptom and the labels assigned to that symptom have been explored. Jones, Wiese, Moore, and Haley (1981) studied 131 undergraduate students at the University of Kentucky with regard to perceived meanings of symptoms. They concluded:

It is important to note that the meaning attached to a particular symptom has implications for physician-patient communications, . . . [and] the patient’s implicit representation of the illness may have important implications for compliance, and the meanings attached to various symptoms of the illness are key parts of that implicit representation. (p. 717)
The instrument used for this study was complex. In addition, the use of the instrument in a sample with at least a high school education makes it less applicable for use in populations with less education. However, the results do support the premise that symptoms and their meanings are unique and key to a person's implicit representation of illness.

In moving towards an understanding of illness representation, Keller and colleagues (1989) discussed the processes of self-care in terms of monitoring sensations and symptoms. The framework from which they presented their work is based on the Common Sense Model (Leventhal et al., 1980). They described the Common Sense Model (see the section on Illness Representation) in detail and also described their studies using the Common Sense Model. In work with cancer patients, healthy adults, persons with hypertension, and the elderly, researchers have reported a similar process when describing the illness episode. Leventhal and colleagues also studied a group of healthy adults to verify generalizability of findings in terms of symptom interpretation regardless of the presence of the illness variable. They stated, “One important implication for self-care activity is that beliefs are important determinants of the symptoms that people choose to monitor in the process of evaluating their health status” (p. 16). They noted that people's representation of their symptoms guides their coping or management.

**Theoretical Framework: Common Sense Model**

The Common Sense Model (Leventhal et al., 1980), because of its simplicity, was selected as the theoretical framework to guide the current study of
symptom interpretation and management in a Mexicana/o population (see Figure 1). The model was developed from the work of Leventhal and numerous colleagues (Cameron, Leventhal, & Leventhal, 1993; Cameron, Leventhal, & Leventhal, 1995; Diefenbach & Leventhal, 1996; Lau & Hartman, 1983; Lau et al., 1989; Leventhal et al., 1980). The work began as an exploration into issues of compliance. Representation is the stage in which people experiencing the symptom begin to organize the information created by the symptom. They use input from bodily sensations, previous experiences, and environmental sources to identify the symptom. Then they order or categorize this information. The five attributes of illness representation (alluded to previously) include (a) identity, (b) time line, (c) cause, (d) controllability (cure), and (e) consequences. They (family or community) label or identify the symptom, propose a cause that allows them to determine a time line (acute versus chronic) for the symptom, and think through the possible “cures” and subsequent consequences of the experience.

The following example illustrates this process: pain in head → headache → probably tension → should not last long → if it does not go away, will take aspirin → did the aspirin help? → yes → probably a tension headache. Taking aspirin is a “coping procedure” (term initially used by Leventhal and colleagues as a neutral term for action). Appraisal involves evaluating the effectiveness of the coping procedure. Continuous feedback occurs among all stages. It is recognized that there is both a cognitive and an emotional aspect to each stage that can influence responses. In the previous example, the cognitive part of this illness representation
Figure 1. Common Sense Model.
is reflected in problem-solving ability, e.g., probably a tension headache → take aspirin → got better. An emotional response may have been evoked had the aspirin not worked, e.g., probably a tension headache → take aspirin → did not work → may be a brain tumor → fear → go to the emergency room. It is acknowledged that the cognitive and emotional interplay may affect problem-solving ability and responses.

Lau and Hartman (1983) and Lau and colleagues (1989) used the Common Sense Model as the framework for their studies of college students. They explored common symptoms and their illness representations in relationship to health locus of control. Their major contributions to this body of knowledge were that the representations students developed for common illness episodes served as templates from which to evaluate potentially serious illness experiences. In addition, the importance of the research was the issue of the controllability of health status. Using the term cure reflects more the biomedical model of disease than a patient-focused illness representation. The major limitation of the studies by Lau and colleagues was their samples. All of their studies were conducted with college students, making the findings difficult to generalize. However, a contribution was made to the further development and refinement of the Common Sense Model.

Ward (1993) presented an overview of the Common Sense Model and its applicability to nursing research. Ward commented:

The use of the Common Sense Model could facilitate knowledge development in nursing because it embraces a stance that is already held by many practicing clinicians, the stance that one of the most crucial elements in therapeutic effectiveness is the clinician’s ability
to understand the patient’s perception of the nature of his/her own illness. (p. 88)

Lowery (1993) argued, however, that the Common Sense Model does not allow for people to look for a cause of their illness. She proposed that the model lacks “room for” the “why me” question and suggested that an underlying assumption of the model is that everyone will have an answer for the cause of his or her illnesses rather than simply accepting that they exist. Lowery concluded her argument with the notion that settling on the Common Sense Model as the model for studying illness perceptions is too limiting and that what is called for is cooperation among scientists in sharing research findings regarding the phenomenon of illness representation. The Common Sense Model is an evolving model. Within the framework of this model, there is room for not applying any one or a number of the attributes in forming a representation.

Diefenbach and Leventhal (1996) updated the Common Sense Model to include social and cultural considerations. They acknowledged that previous discussions of the model lacked cultural applicability, but they emphasized the importance of cultural context in forming illness representations. They stated, “Culture will determine which of many symptoms will be reported among those associated with a given disease . . . [and] . . . the symptomatic focus establishes expectations for treatment” (p. 25).

Although this model has not been specifically applied to the study of ethnically and culturally diverse populations, the process of assessing illness representation afforded by the “common sense” approach served as a useful
framework in which to conduct the current study. This framework guided the research questions in a conversational manner that was both nonthreatening and a socially acceptable form of communication within the Mexicana/o community.

**Latina/o Symptom Management**

It was important to examine the current literature with regard to Latina/o symptom management as it influenced the present research. In addition, folk medicine beliefs and practices that influence symptom management were critically reviewed. Although none of the following studies used the Common Sense Model as a guiding framework, in retrospect, each of the studies implicitly demonstrates concepts of the Common Sense Model.

**Beliefs**

In a study of the hot-cold theory of disease in Puerto Ricans, Harwood (1971) used observations, a questionnaire, and anecdotal reports to obtain data. It is unclear what the sample size was for this study or the quality of the data collection. Acculturation was identified as a factor affecting how entrenched this hot-cold theory was for this group of Puerto Ricans. This theory “stems from Hippocratic humoral theories of disease which were carried to the Western hemisphere by the Spanish and Portuguese in the 16th and 17th centuries” (p. 1153). In this system, a “cold” disease such as arthritis should be managed with “hot” modalities. Arthritis, colds, and menstrual periods were identified as *frio* (*cold*), whereas constipation, diarrhea, and ulcers were identified as *caliente* (hot).
Milk of magnesia was identified as *frio* and castor oil as *caliente*. A banana was *frio* and chocolate was *caliente*. Incorrectly applying this paradigm of healthcare could prolong the illness being treated.

In Los Angeles, California, Kosko and Flaskerud (1987) examined beliefs about the cause and treatment of chest pain in 90 subjects. Three groups (*n* = 30) were recruited from within a conventional healthcare setting. Mexican Americans, Anglo laypersons, and Anglo nurse practitioners completed a questionnaire regarding their beliefs about the cause and treatment of chest pain. The study was conducted in English. Mexican Americans were significantly different from both of the other groups in their folk beliefs about chest pain. They believed that chest pain was a result of a fright experience, which is treated with hot liquids. They also believed that good health is a matter of good luck. The Anglo groups stated that chest pain was a symptom of heart problems. No within-group difference was found for the groups. Kosko and Flaskerud identified chest pain as a common complaint in the Mexican American population and concluded that developing an understanding of their beliefs could positively affect care provided to this population by nurse practitioners. The obvious limitations of this study were the small sample size and no Spanish-speaking Mexican Americans, who might have changed the within-group results of the Mexican American group.

Both of these studies identified a way of thinking about illness and treatment that is different from that of conventional healthcare (Harwood, 1971; Kosko & Flaskerud, 1987). These studies also suggested that developing a better
understanding of the emic perspective would allow the clinician to incorporate the perspective into an overall plan of care, possibly decreasing morbidity and mortality.

Symptom Management in Latina/os

Gordon (1994) used a focus-group approach of 11 Spanish-speaking women identified as Hispanic attending an English-as-a-second-language class to address two research questions: (a) How do Hispanic health beliefs affect healthcare practices? and (b) What actions are taken to treat symptoms of illness or injury? Gordon used Leininger’s (1991) culture-care theory as the framework for this study within a mini-ethnographic study design. The discussion and subsequent data analysis explicated 75 symptom and treatment statements, revealing a process used by these women that Gordon described as “comparable to the nursing process—assessment, plan, and evaluation” (p. 316). Themes included home remedies in general, remedies for common symptoms and conditions, and remedies for less common ailments. The symptoms and conditions mentioned included fever, diarrhea, flu, earaches, burns, diabetes, and kidney stones. Gordon labeled the symptoms and conditions as health beliefs and stated that these remedies were validated by group agreement in terms of symptom and condition management. Gordon then identified mutual respect, listening, and negotiation as skills that would benefit nurses when caring for patients. Although Gordon discussed “health beliefs,” there was no discussion of actual beliefs that might encompass more than
the identity of the symptom and condition presented. The sample size was small (one focus group), and there was no discussion of the heterogeneity of the group.

In a community clinic in rural central California, Mikhail (1994) interviewed 100 Latina/o women (98% with ethnic origins in Mexico and 2% originating from Central America and South America) regarding their beliefs about (and management of) fever, cough, diarrhea, vomiting, conjunctivitis, skin rash, minor wounds, and burns for their children. She identified mothers' beliefs about etiologies that were based on several misconceptions, folk beliefs, and a lack of knowledge. The majority (81%) of the women used home remedies prior to seeking assistance from conventional healthcare providers. Mikhail described the remedies used, which varied according to the problem, including herbs, teas, enemas, ointments, and applications. The author concluded with a discussion about the need for cultural competence. This clinic-based study is an excellent contribution to the folk medicine literature describing Hispanics. Mikhail identified the most common problems for which these women typically sought treatment for their children at the clinic and then used these “most common problems” as the focal point of the inquiry. One limitation of this study is that it was clinic-based. In other words, the women had to have made the decision to use conventional healthcare. In addition, the “most common problems” for women who care for their children outside of the clinic system may be only a small portion of their daily healthcare problems. Finally, the study addressed symptoms in children only.
Browner (1980) studied the management of amenorrhea in Colombian women. In this study, Brown found that these women had a complex belief system about amenorrhea such as a possible symptom of pregnancy. They used abortifacients comfortably within this belief system, which allowed for the management of fertility in a society that does not support abortion.

An ethnographic study conducted in the rural Mexican village of Pichataro provided a detailed accounting of symptom interpretation and management in a medically pluralistic environment (Young & Garro, 1981). This study described the medical decision making used by the residents to cope with symptoms once they were identified. Young and Garro proposed a theory with regard to medical decision making based on four factors: (a) gravity of illness; (b) availability of a home remedy; (c) success of a home remedy; and (d) barriers to care such as costs, availability, and transportation. This theory provided a template from which Young and Garro examined symptom interpretation and management in the village of Pichataro. They found repeated support for these four factors in the residents' interpretation and management of symptoms.

It is evident from these studies as well as from previously reported studies in the section on folk medicine that Latina/os have a complex system for interpreting and managing symptom or illness episodes. A few of the researchers preselected the symptoms that were examined. The only studies that were not clinic based were those conducted in other countries as ethnographies and Gordon's (1994) study conducted in a school setting. The research examining Latina/o
symptom interpretation and management is limited, but it could be enhanced by applying the ethnographic approach to Latina/o communities in the United States.

Summary

As the face of the nation changes and becomes more culturally diverse, it is imperative that clinicians strive to increase cultural competence. There is much rhetoric today about cultural competence, but the issue is one of a lack of research examining diverse ethnic and cultural healthcare practices. It is important to examine how people are using the healthcare system in the United States. Using the conventional healthcare system in the United States no longer can be considered “the only way.” The integration of healthcare beliefs and practices from ethnically and culturally diverse populations into conventional healthcare will give clinicians better tools with which to care for patients.

Due to the paucity of research on Latina/o healthcare and more specifically on symptom interpretation and management, the current research contributed knowledge pertinent to the development of increased clinical cultural competence. The special contribution of this research is that it was community based, examining symptoms that the Mexicana/o participants selected. As in many studies, minimal limitation was present in the investigation because of an inability to speak English. The current study focused on Mexicana/os in particular, as the great diversity within the Latina/o community was acknowledged. A lack of information with regard to Latina/o symptom interpretation and management from the emic perspective was addressed. The goal of this research was to add to the clinicians’
cultural competence through an understanding of Mexicana/o symptom interpretation and management.
CHAPTER 3

METHOD

This study of common symptom interpretation and management in a 
Mexicana/o population was undertaken using a qualitative research paradigm. 

Creswell (1998) defined qualitative research as

an inquiry process of understanding based on distinct methodological 
traditions of inquiry that explore a social or human problem. The 
researcher builds a complex, holistic picture, analyzes words, 
reports detailed views of informants, and conducts the study in a 
natural setting. (p. 15)

Many factors made the use of qualitative research an appropriate approach for this 
study, including the research questions, the exploratory nature of the study, the 
search for a detailed view of the topic, and the importance for studying the 
phenomenon in a natural setting (maintaining context). The ethnographic method 
for this study of Mexicana/o symptom interpretation and management was selected 
in order to “build” a complex holistic picture of the phenomenon.

Ethnography

Ethnography has its roots in anthropology. Leininger (1985) defined 
ethnography as

the systematic process of observing, detailing, describing, 
documenting, and analyzing the lifeways or particular patterns of a 
culture (or subculture) in order to grasp the lifeways or patterns of 
the people in their familiar environment. (p. 35)
The use of ethnography as a method for conducting research is useful when studying "the routine, daily lives of people" (Fetterman, 1998, p. 1). The focus of ethnography is to study people in their own environment from their own "emic" (insider) perspective. Data collection for this type of study is accomplished in many ways, including interviews, participant observations, photographs, and a review of documents. The key to ethnography is (a) that the researcher is an "instrument" in the study, (b) that the study is conducted in the native environment to elicit information from the emic perspective, and (c) that the study is presented with the "etic" (outsider) interpretation or explanation.

Congruent with published criteria (Leininger, 1985), ethnography was selected for the following reasons: (a) to have no knowledge or limited knowledge about a phenomenon; (b) to grasp the totality of the human lifestyles of individuals, families, and communities from their perspectives and their ways of knowing; (c) to collect data about new questions and inquiries by researchers; (d) to obtain meanings-in-context data; (e) to generate concepts, theories, or hypotheses; (f) to identify variables for study; (g) to make a cross-cultural study of human phenomenon; (h) to identify recurrent and patterned lifeways of people; and (i) to provide in-depth accounts of events, situations, and circumstances that may be difficult to find any other way.

Leininger (1985) differentiated between two types of ethnographic inquiry: (a) mini-ethnography and (b) maxi-ethnography. A mini-ethnography is defined as a "small-scale ethnography focused on a specific or a narrow area of inquiry" (p.
35), whereas a maxi-ethnography is a “large and comprehensive study of general and particular features of a designated culture” (p. 35). The current study was a mini-ethnography that focused on a narrow area of inquiry rather than on general features of a culture as would be done in a maxi-ethnographic study.

Stewart (1998) described a process for evaluating the quality of ethnographic inquiry. An examination of this mini-ethnography for veracity (validity or verisimilitude of depiction), objectivity (reliability or transcendence of perspectives), and perspicacity (generalizability or applicability of insights elsewhere) is presented in Chapter 5.

Prefield-work Preparation

Ethnographic inquiry is undertaken in the field and outside of the controlled environment of a laboratory setting. Preparation prior to entering the field and to beginning interactions with the community, key informants, and participants is imperative to the success of an ethnographic study. The following steps were undertaken to prepare for the field-work phase of the study.

Reflexivity

Burns and Grove (1997) defined reflexivity as a process through which “the researcher examines personal feelings and experiences that may influence the study and integrates this understanding into the study. This process requires a conscious awareness of self” (p. 531). It was important for me, as an instrument in the study, to identify my beliefs about the phenomenon and the people with whom I
interacted; therefore, reflexivity was crucial. I believe that (a) people are resourceful problem solvers; (b) people will practice self-care, including home remedies and folk medicine, as a first line of defense in solving their healthcare problems; (c) people act to solve these problems with the best of intentions regardless of the outcome; (d) Mexicana/os have a well-developed sense of self-care modalities, which may include use of the conventional healthcare system; (e) the study group cared for themselves based on their own culturally based belief system; (f) a strong sense of family exists and must be acknowledged; and (g) culture may or may not influence depictions of the illness episode. These beliefs helped me to understand how to enter the field-work phase of this study with a respect for the culture and a curiosity regarding these peoples' resourcefulness and problem-solving abilities. I wondered if I would be able to set aside my preconceived Anglo worldview during all phases of the study.

Backtranslation

The process of backtranslation was first described by Brislin (1986). The process is used when bilingual materials are needed for a particular study. First, the material is written in the native language of the researcher and then translated into the native language of the participant by someone who is bilingual. A second bilingual person completes a translation back to the original language in which the material was written. Any discrepancies that arise in the material once it is translated back are discussed between the researcher and the translators until agreement is reached regarding the appropriate language to use. The goal of
backtranslation is to assure the researcher that what is being asked or explained in the researcher’s language is the same concept being asked for or explained in the participant’s language. This process was used for the bilingual material utilized in the study.

**Pilot Study**

After obtaining approval for the study from the University of Utah Institutional Review Board, a pilot study was conducted to evaluate the efficacy of the Semistructured Interview Guide, which was designed to explicate the symptom experience. The Semistructured Interview Guide (see Appendix A) was designed to directly explicate the symptom experience using the phases of the Common Sense Model for question development. Each question addressed a phase of the Common Sense Model, such as representation, or a subphase, such as representation, or timeline. One interview was conducted in English with a Mexican American woman using the original guide. The questions were found to be too direct and did not allow for spontaneous responses. The intent of the interview process was to allow stories to evolve about the symptom experience rather than to have interaction mimic taking histories during a healthcare encounter, which tends to be very focused in eliciting simple answers to direct questions. The Modified Interview Guide (see Appendix B) was developed that allowed for more spontaneous responses, probes, and questions. Still using the Common Sense Model to guide the questions, I incorporated a more conversational approach into the interview process, thus establishing an environment for a “chat” rather than for an
"inquisition." The Modified Interview Guide also more specifically addressed the medically pluralistic environment where the symptom experience occurred. One bilingual Mexicana woman and one Spanish-speaking Mexicana/o couple were interviewed using the Modified Interview Guide. Responses were more spontaneous and richer in content. Approval for the use of the Modified Interview Guide was obtained from the Institutional Review Board.

The pilot study also afforded an opportunity to test the quality of an audiotape recorder, the quality of a translator for Spanish-only interviews, and the quality of transcription. The quality of the recordings was adequate for transcription and review when placed on a table between the research assistant, the participants, and me. The first research assistant was a male native of southern Mexico for whom English was a second language. Even after an orientation regarding the process, the first research assistant proved to be inadequate for this study due to inaccurate translation and an inability to relax during the interview process. This style created an environment of formality that was not conducive to spontaneous responses from the participants. The transcription of audiotapes by a bilingual (Spanish/English) transcriptionist was accomplished; however, initial estimates of time for transcription with translation was calculated at a 2:1 ratio (2 hours of transcription time for every 1 hour of interview). In fact, a 6:1 ratio was needed. After discussing the pilot study interview with the bilingual transcriptionist, I asked her (a female from Spain) to be the research assistant as well. She had the advantage of having done the initial transcription, and she had
heard my concerns and critique. The first Spanish-only interview was conducted with little difficulty. Translation during the interview was cleaner; nuances were included in the transcription since she was present for the interview; and simpatia (good interpersonal skills) were achieved among the research assistant, the participant, and me. The bilingual transcriptionist (a female from Spain) provided translation for the Spanish-only interviews for the main study and also served as the transcriptionist. This dual role provided continuity that decreased transcription time (a 4:1 ratio) and improved the quality of transcriptions.

The pilot study resulted in using the Modified Interview Guide (approved by the Institutional Review Board) and in using the female bilingual transcriptionist who served as the research assistant for the bilingual interviews. The process was smoother since the research assistant was relaxed and conversed easily with the participants. One factor that may have promoted more effective interviewing was that she was female and the Spanish-speaking participants were female. (There were two male participants; however, they spoke English only.) Rapport during the interviews with all women was more relaxed than with the presence of a male.

Gaining Entry

Since I was not a member of the cultural group being studied, gaining entry into the group was crucial. The concept of gaining entry has been described in detail by numerous authors and was especially important to the outcome of this study (Creswell, 1998; Fetterman, 1998; Leininger, 1985; Moreno & Lopez, 1996; Morse & Field, 1995). Gaining entry was the process used to negotiate entrance
into the study community.

Entry was guided by a number of cultural concepts that Moreno and Lopez (1996) described as *respeto* (respect), *confianza* (trust), and *simpatia* (good interpersonal skills). Recognizing the importance of *la familia* (the family) also was important (Caudle, 1993). These concepts were incorporated into my interactions in all phases of the study. Each encounter was guided by these concepts from telephone contact to face-to-face interactions.

This process was initiated by securing a dissertation committee member who was of the same culture as the study participants. This member's role was to ensure cultural accuracy in the research process and the accurate portrayal of cultural norms for this particular study as well as to provide initial contacts within the Latina/o community. The next phase to gain entry was the interaction with key informants (persons with knowledge of the culture and community but not the study participants) in the Latina/o community. The key informants served as gatekeepers to the Latina/o community, sharing information about the culture, issues that impact members of the Latina/o community, and stories about their lives as Latina/os in Utah. Recommendations from key informants directed the next phases of the study, which were conducted concurrently: (a) participant observation and (b) participant interviews—both of which are discussed in more detail later in this chapter.
Cultural Immersion

An important part of any ethnographic study is cultural immersion (Burns & Grove, 1997; Leininger, 1985). For this study, the Chicana committee member initially directed my cultural immersion. Recommendations of major literary works that reflected the nuances of the Mexicana/o culture served as an initial introduction. Included in the process of cultural immersion was exposure to Mexicana/o music, film, and community activities (see Appendix C), which are discussed in greater detail in Chapter 4. Cultural immersion is a matter of degree that is affected by time, quality of exposure, and receptivity on the part of the researcher. Since it is difficult to determine when a nonmember of a group would be culturally immersed enough to grasp cultural nuances, approval by the Chicana committee member that exposure was adequate was used as an endpoint. The prefield-work preparation, including reflexivity, backtranslation, pilot work, gaining entry, and cultural immersion, provided me with a basic understanding of the culture and tools necessary to conduct the interviews, which were the core of the data collection process.

Sampling

The process of sampling was directed by the nature of the study. For example, since I was studying Mexicana/o symptom interpretation and management, it would not have been beneficial to spend time at the Jewish Community Center. Both the community and key informants were selected based on their ability to contribute to the overall contextual nature of this study: to focus
on Mexicana/o symptoms. Inclusion criteria were developed specifically for the selection of the study participants.

Community

In order to obtain meanings-in-context, it was important to identify a community where Mexicana/o participants lived, worked, and played. The Chicana committee member recommended a community contact as appropriate for directing this selection. The community contact was an active member of the Latina/o community at large as well as a member of an ethnically diverse community on the west side of Salt Lake City, Utah. He was a well-respected Mexicano who had worked as a teacher and activist and who had run for public office during the course of the study. Upon the recommendation of this community member, I selected Poplar Grove, a community on the west side of Salt Lake City, Utah, as the research site. Due to his familiarity with the community, the key informant chose this area because of its large Mexicana/o population and its lack of healthcare resources. The community is described in Chapter 4.

Key Informants

Purposive sampling was used to engage key informants (Burns & Grove, 1997). Each key informant \( n = 22 \) was contacted upon the recommendation of other key informants or for his or her role in either the Latina/o or Poplar Grove community. Included in this sample were community leaders and representatives of agencies serving the needs of the community. No predetermined sample size for
key informants was established.

Participants

A convenience sampling method was used for this mini-ethnography (Burns & Grove, 1997). Gaining entry and serendipity influenced this type of sampling. Although biases exist with this type of sampling due to participant self-selection, inclusion and exclusion criteria were developed to guide the sampling for the study.

Inclusion criteria for the study included the following: (a) 18-years-old or older, (b) of Mexican heritage, and (c) a resident of Poplar Grove. No one was excluded based on language, gender, or chronicity of illness.

Although members of this culture may have been more comfortable conversing in small groups, pilot study data demonstrated that the complexity of transcribing audiotaped group interviews in multiple languages resulted in large portions of unusable data. Each participant provided an individual interview conducted in his or her language of choice. Demographic data were collected at each participant encounter (see Appendix D). The sample size ($n = 18$) was limited by time (I withdrew from the field after 9 months) and ability to recruit participants. In terms of data saturation, the study did not narrow the focus of research to a particular symptom; therefore, it was impossible to reach data saturation with regard to a particular symptom experience with this sample size ($n = 18$). However, redundancy did occur in terms of how the stories were told regardless of symptom.
Setting

The interviews were conducted in the participants’ homes or locations of their choice. The symptom interpretation and management experience are dealt with more often in the home environment, and they create the context within which the symptom occurred. Because it was important to create an overall portrait for the phenomenon, I found observation of the home environment to be contributory to the participants’ stories. With the exception of 1 interview that was conducted at the participant’s place of employment (sitting on a school bus), all of the interviews were conducted in the participants’ homes. Fourteen of the interviews were conducted sitting at the kitchen table, 2 were sitting in the living room, 1 was sitting in a grandchild’s bedroom with the tape recorder propped on a hamper, and 1 was sitting on a school bus with the tape recorder balanced on my knees.

Procedure

Although the initial literature review focused on professional literature, immersion into the culture from a literary perspective was helpful. This immersion created a backdrop for the participants’ stories and gave me a sense of perspective.

After obtaining Institutional Review Board approval and completing the pilot study, I selected a community with the assistance of a key informant. I began the process of gaining entry into the community by participating in community meetings; meeting with local key informants; and spending time in and around various businesses, schools, and churches. During each encounter, I spoke either formally or informally to persons in the community about the intended research,
and I received information that led to the development of the community portrait.

**Key Informants**

Each key informant was contacted by telephone. Meetings with key informants were held in their places of business, but with four exceptions. One key informant meeting was held at a Poplar Grove taqueria, and it concluded with a driving tour of the community. Two key informant meetings were conducted as telephone conversations. One key informant interview was conducted by mail. Field notes provided written documentation of the meetings. The field notes were entered into the database and included in the analysis.

**Recruitment of Participants**

The recruitment of participants proved to be the most challenging part of this research study. Key informants created an atmosphere of trust by introducing me to persons living in the community. These introductions afforded me the opportunity to begin interviewing study participants. I approached possible study participants at schools, restaurants, stores, churches, other businesses, and parks. The most productive participant response came by bilingual flyers (see Appendixes E and F) that were sent home with school children at two of the local schools (after a $20 cash incentive was approved by the Institutional Review Board). Other methods of recruitment, including directly approaching members of the community in public places, setting up a recruitment poster at community events, and having direct referrals, were used, but they were unsuccessful.
I provided a bilingual telephone message for participants who called in response to the flyer. Appointments for interviews were arranged with participants at a place (usually their home) and time of their choice. A research assistant returned telephone calls to arrange interviews with participants who requested Spanish-language meetings. Telephone calls to verify the time and place of the interview were made 1 day prior to the actual interview.

**Interviews**

Interviews were conducted in the homes of the participants, but with the exception of one participant who wanted to be interviewed where she worked (sitting on a school bus). All interviews were conducted during daytime hours at a time requested by the study participants. After written consent to participate was obtained (see Appendixes G and H), each interview was audiotaped. The bilingual research assistant was present for six interviews. Upon completion of the interviews, the $20 cash incentive was paid.

Each interview lasted from 60 to 90 minutes. The more animated the participant was, the longer the interview. Engagement in the process was not limited by language. One Spanish-speaking participant was so engaged in the process that she broke out in song when describing the use of an over-the-counter cough preparation. An English-speaking participant answered each question or probe with a simple yes, no, or a three- to four-word sentence. I gave her the opportunity to conduct the interview in Spanish; however, she spoke only English. Her educational preparation was at the eighth-grade level, which may have
contributed to the simplicity of the interview. For many of the participants, when asked about common problems, they simply stated, "We are not sick." However, for all of the participants, the most engaging responses came when asked about the use of the emergency room or how they would change the healthcare system.

Interviews were transcribed by 2 transcribers. The bilingual research assistant transcribed the Spanish interviews. A professional transcriber transcribed the 12 English interviews. I read each transcript while listening to the audiotape upon receipt of the transcription. I returned the transcripts to 6 participants (4 English, 2 Spanish) to verify the translation. Each of these participants was given a copy of the transcription from his or her interview and was asked to review it for accuracy. Each of the participants stated, "It's fine." I had mixed feelings about this response. Either the interviews were "fine" or there may have been an intimidation factor at play. That is, this culture tends to be very respectful of persons with "more education," and they may have believed that any criticisms of the interviews (and, therefore, me) would have been disrespectful. The meaning of these responses is unclear to me.

Participant Observation

I recorded field notes and took photographs during each community event in which I participated. I was asked to make presentations at two community meetings regarding the study. I attended celebrations in the Latino community, partaking of the food and commerce at each event. One local taqueria provided me with many opportunities to listen to mariachi music, eat Mexicano food, and listen to
conversations of the local people. All of these experiences were recorded in field notes as soon as I exited the site. This information was entered into the database for analysis.

Photographs

Photography was included as a method of data collection because of its ability to capture data that are otherwise indescribable. Only 2 participants agreed to be photographed (Plate 1 and Plate 2) for the study. Consent was obtained prior to photographing the study participants (see Appendixes I and J). Photography of the Poplar Grove community and events in the Latino community were stored on disks, CD-ROMs, and photographs. Each photograph was labeled and placed in a plastic cover sheet.

Description of Data Sources and Data Collection Experiences

Data collection included meetings with key informants and participant interviews. Participant observation and a review of the literature (e.g., fiction, film, and music), documents, photographs, and artifacts were also a part of the data collection process.

Meetings With Key Informants

Key informants were defined as persons from the Latina/o and Poplar Grove communities who could contribute information to the development of a community portrait from which the symptom experience would be explicated.
Plate 1. First participant in study.
Plate 2. Study participant.
When interviews with key informants were conducted in similar settings (e.g., school and clinic), the interview format was standardized (see Appendix K) to allow for comparison across interviews. Once I explained the purpose of the interview, the remainder of the key informant meetings was conducted using an informal format. I recorded key informant meetings as field notes during the course of the interview. Since these interviews were conducted in order to provide background information and guidance for study implementation, the field notes from the meetings were not subjected to the same rigorous analysis as the participant interviews.

The stories of the key informants \( (n = 22) \) were essential to building the community portrait. The key informant pool was composed of clinic directors, school principals, neighborhood housing authority representatives, community center directors, representatives from the police department, a city council person, a community activist, a community council chairperson, program directors for services to community members, a school superintendent, a university professor, and two leaders from the greater Latina/o community. Their stories told of the Latina/o community’s struggle to deal with issues of exclusion, efforts to increase inclusion, and difficulty in realizing the potential for the Latina/o community as a whole—more specifically, the Mexicana/o community in Poplar Grove. Each key informant discussed his or her role in society and then shared personal stories about challenges he or she faced as a Latina/o in Utah or in his or her interactions with Latina/os and others in Utah. These stories were used to form a contextual
base from which I was able to place the participants’ symptom experiences.

**Participant Interviews**

Interviews with participants were audiotaped. When appropriate, I took notes during the interviews. These notes provided another source of information with regard to the environment where the interview took place, and they also were used for emphasis of information shared by the participants. Demographic data were recorded on the demographic tool (see Appendix D).

Eighteen people who identified themselves of Mexican heritage, 18 years old or older, and residing in Poplar Grove were interviewed. Of these people, there were only 2 (11%) males. Interviews were conducted in Spanish with 6 (33%) participants, and the remainder was conducted in English. The participants ranged in age from 22 years old to 63 years old, and 12 (66.6%) were married or living with a partner. Two thirds \( n = 12 \) of the participants were Catholic. Only 6 (33%) participants were born in Mexico. The majority of participants \( n = 12 \) had a high school education or less. Thirteen (72%) of the participants reported income levels at or below 200% of poverty (Federal Guidelines, 2000).

Demographic details are presented in Table 2.

The majority (56%) of participants used the services of the Northwest Community Health Center, with only 6 having private physicians. Only 2 participants reported using the Neighborhood Clinic services. Many participants used services provided at InstaCare but found them to be “too expensive.” Two participants reported using University of Utah clinic services. The *Centro de Salud*
Table 2

Demographic Characteristics (n = 18)

<table>
<thead>
<tr>
<th>Category</th>
<th>Details</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gender</td>
<td>Female = 16, Male = 2</td>
</tr>
<tr>
<td>Age</td>
<td>Range = 22 to 63 years, Mean age = 37.8</td>
</tr>
<tr>
<td>Marital status</td>
<td>Single = 2, Married = 9, Living with partner = 3, Separated = 1, Divorced = 2, Widowed = 1</td>
</tr>
<tr>
<td>Religion</td>
<td>Catholic = 12, The Church of Jesus Christ of Latter-day Saints (LDS or Mormon) = 1, Other = 5</td>
</tr>
<tr>
<td>Education</td>
<td>0 to 8 years = 2, 1 to 3 years high school = 4, High school graduate/general educational development certificate = 6, Some college = 3, Associate of arts degree = 3</td>
</tr>
<tr>
<td>Annual income</td>
<td>&gt;$5,000 = 3, $5,000 to $9,999 = 6, $15,000 to $19,999 = 4, $20,000 to $29,999 = 4, $30,000 to $39,999 = 1</td>
</tr>
<tr>
<td>Place of birth</td>
<td>United States = 12, Mexico = 6</td>
</tr>
<tr>
<td>Years in United States</td>
<td>Range = 2 to 63, Mean = 32.8</td>
</tr>
<tr>
<td>Years in Poplar Grove</td>
<td>Range = 17 to 32, Mean = 11.6</td>
</tr>
<tr>
<td>Work</td>
<td>None = 4, Part time = 5, Full time = 9</td>
</tr>
<tr>
<td>Insurance</td>
<td>None = 7, Medicaid = 4, Medicare = 1, Private = 6</td>
</tr>
<tr>
<td>Clinic</td>
<td>Community center = 10, University clinic = 2, Private physician = 6</td>
</tr>
</tbody>
</table>
Familiar clinic was not open when 16 of the interviews were conducted but was open for the last 2 interviews. These participants were not familiar with the clinic. The new clinic site is located within the study site’s boundaries, and it offers bilingual services and flexible hours—factors that could have influenced participant choice of healthcare facilities.

Acculturation was assessed when using one factor (language) of the SASH (Marin et al., 1987). As previously discussed, there is some debate about measuring acculturation; consequently, four questions were included with regard to using the Spanish language (Marin & Marin, 1991). These questions were incorporated into the Demographic Information tool (see Appendix D). Each question is scored as follows: 1 = Spanish only, 2 = Spanish better than English, 3 = both equally, 4 = English better than Spanish, and 5 = English only. Points are averaged for a language factor acculturation score (0 = least acculturated and 5 = most acculturated). Reliability of the original instrument demonstrated internal consistency (alpha coefficient = .92 for 12 items [language] and alpha coefficient = .90 for 5 items [language]). Validity was demonstrated by the ability of the instrument to discriminate between generations, to measure length of residence, and to discriminate between different ethnic groups. Since language use accounted for 54.5% of the overall variance of acculturation scores in previous research, only this section was used to decrease participant burden. In summary, this instrument has been used extensively with consistent evidence to support its reliability and validity (Barona & Miller, 1994; Marin & Marin, 1990, 1992;
Marin et al., 1993; Norris et al., 1996; Sabogal et al., 1995). All of these studies included Mexican Americans.

For these participants, acculturation scores ranged from 1 to 5 (see Figure 2) (5 = most acculturated persons in terms of language use and 1 = least acculturated persons in terms of language use) (Marin & Marin, 1991). Using these criteria, being more acculturated meant speaking in English, and being less acculturated meant speaking in Spanish. The mean acculturation score for this study group was 3.03. Six (33%) participants scored less than 2.75, 5 (28%) participants scored more than 3.75, and the remaining participants’ scores (39%) were from 2.75 to 3.75.

Symptom Experience

Questions that specifically addressed the symptom interpretation and management experience were developed using an explanatory model approach (Kleinman, 1980; McSweeney, Allan, & Mayo, 1997). The Modified Interview Guide (see Appendix B) also elicited information from participants with regard to alternative healers, use of the emergency room, and how they would change the healthcare system.

Field Notes

The use of field notes was limited to brief notations during each encounter with the participants; however, the notes were extensive when meeting with key informants. Although the original intent was to audiotape key informant meetings
Figure 2. Distribution of acculturation scores.
as well as participant interviews, a number of limiting factors (e.g., difficulty securing a transcriptionist and cost of transcription) made the use of field notes during key informant meetings the only method of recording information. After each encounter, my field notes and impressions were included as part of the data analyzed.

An example of field notes taken during the third participant interview is presented in Figure 3. This participant used drawings to clarify a point for my research assistant and me when we were discussing the management of her diabetes.

**Participant Observation**

Data collection through participant observation is a unique feature of ethnographic methodology. It has been argued (Fetterman, 1998) that, if the researcher does not participate but simply observes, the researcher is not conducting an ethnographic study. However, Leininger (1985) described various degrees of participation (from observation only to participating in the event)—all of which are acceptable methods of data collection through participant observation. Key informants invited me to participate in many types of events (n = 16) in the Latino community and in Poplar Grove. The events varied from meetings at which I was asked to present the proposed research to celebrations of the Latino culture. I spent time observing local businesses and interacting with teachers, parents, and children at local schools. Time also was spent observing the people of Poplar Grove at church and at local parks. Depending on the event, my level of
Figure 3. Example of field notes.
participation varied. When possible, photographs were taken during participant-observation events. After each event, I hand wrote the field notes. A more complete description of the event and my impressions were recorded on a home computer.

The use of participant observation as a method for adding context to the symptom experience is valid. Many opportunities such as attendance at a local church and participation in city council and community council meetings presented themselves, which allowed exposure to the Latino and Mexicano culture. Time spent in local businesses observing people interacting in activities such as eating, grocery shopping, buying baked goods, and making purchases at the local botanica gave me a glimpse of everyday life. Interacting with parents and teachers at an elementary school and observing activities at the local library also were insightful. Attendance at major events celebrating Latino and Mexicano culture provided opportunities to observe firsthand a celebratory part of the culture. A walk through the International Peace Gardens (a place that the west-side communities of Salt Lake City are using as a neutral place in which to create a sense of community) gave me a sense of international community and a time for contemplation. Each of these participant-observation experiences served as data to enrich my understanding of the study participants and their community.

Many times during the course of community observation I had the opportunity to eat at a local taqueria (a Mexicano eatery). A “typical” key informant identified this place. Following is a description of my experience on a
particular visit to this taqueria (see Plate 3):

I had eaten at Marisco’s many times. I always ordered the same thing: carne asada burrito and orange slice. My order was taken in English. On this particular day I sat in a corner booth so I could watch the activity as the place quickly filled with the lunch crowd. Construction workers, a couple with small children, and an older couple ordered and sat down. All of the persons were speaking Spanish. Quarters were dropped in the juke box and mariachi and salsa music poured loudly from it. Everyone talked animatedly, greeting those at other tables. The children pointed at me. The men boldly stared and then turned away laughing. The women working in Marisco’s set trays on the countertop and started calling out numbers. I waited for my number to be called: “ochenta uno, ochenta dos, ochenta tres, ochenta quatro, eighty-five.” My face turned red as I walked across the taqueria to pick up my food. For the first time I had a sense of what it must be like to be different.

This experience provided me with a different perspective from which to frame the current study insofar as I was able to sense, to a small degree, what it is like to be seen as different from the majority. For me, living as a privileged, Anglo female, I felt awkward and out of place, vulnerable. This experience humbled me.

Photography

The use of photography served as an additional data collection method. Photographs provided detail, color, and richness for the development of the community portrait within which the symptom interpretation and management experience took place. The primary use of photographs was a visual reminder of the community and its participants during data analysis as well as for use in presentations. Although few participants agreed to be photographed, I photographed the community and multiple events that are part of the
Plate 3. Marisco's taqueria.
Latino/Mexicano community \((n = 83)\). Photographs were stored in plastic cover sheets and labeled as to time, place, and event.

Photography as a data collection method was invaluable. For the current study, the photographs provided a pictorial journey through the Poplar Grove community. The contrasts that existed in the community were captured in photographs. Photographs are included in the presentation of the research findings.

**Literature and Documents**

The use of Latino/Mexicano literature provided a contextual grounding for the study itself and gave me an introduction to cultural immersion. I reviewed historical documents, fictional literature, films, newspaper and magazine articles, media clips, and textbooks. These sources served to locate the study within a Mexican/Mexicano historical perspective as well as to enhance and validate information gathered during the study itself. A list of these sources identified for use in my cultural immersion is included in Appendix C. The initial selection of literature was guided by a committee member and then serendipity once immersion was underway. As part of the overall immersion in the cultural experience, I read, viewed, and listened to literature from the Mexicana/o culture. A list of the literature appears in Appendix C. The first book I read, *Bless Me, Ultima* (Anaya, 1972), was recommended by the Chicana committee member and a key informant. From the first sentence of the book, the reader is drawn into life on the *llano*, the story of Antonio, a boy struggling with his entry into the outside world. This book weaves a complex story of family tension and synergy and is mixed with clashes of
old and new cultural experiences. Anaya's writing gives the reader a detailed portrait of Mexicana/o life, which was created from the Chicano writer's life experiences.

This contrast of old/new, male/female, and Mexicano/Anglo was a recurrent theme in the literature. Although exposure was limited, *The Milagro Beanfield War* (Esparza & Redford, 1988), *Selena* (Esparza, Katz, & Nava, 1997), and *Mi Familia* (Thomas & Nava, 1995) all portrayed the Mexicana/os as people of passion, energized by the tensions created by the clash of their "old world" ways and those of the encroaching Anglo world. Other documents obtained during the course of my field work were included when they lent themselves to enhancement of the data; otherwise, they were used as background material only and stored with other data.

Through the course of this study, many documents were collected. Each agency offered brochures, flyers, and informational pieces about the services they offered. Minutes from meetings of the community council and a subcommittee of the Salt Lake City Council were collected as well. A resource book and report from the Department of Youth Corrections were part of documents gathered at a community council meeting. Key informants gave me a neighborhood cookbook and maps of the area. A local businessman provided a copy of the Latino *Amarilla Pagines* (telephone book). A key informant also shared reports that were authored by the Department of Family and Consumer Studies at the University of Utah describing the west-side communities of Poplar Grove and Glendale. Although
there were many other documents collected during the course of this study, the most pertinent have been listed.

Music was used as ambience during participant observation and data immersion. I attended numerous events where the music provided the heart and soul of the experience (see Plate 4). The rhythm of the music provided me with a sense of something different than myself, yet drew me in as I listened and watched people dancing and singing. In summary, exposure to the written word and music allowed me to gain a valuable sense of the Mexicana/o culture while exploring its complexity. Much of this complexity is presented in Chapter 4.

Artifacts

I purchased artifacts from a local botanica as examples of available treatment modalities. These artifacts included prepackaged herbs, a candle, and a book describing the uses of herbs and incense for magical purposes. Pictures of these artifacts are included in Chapter 4. Although refreshments often were served as part of the ritual beginning the interview process, there were no opportunities for the collection of artifacts from the participants. One participant gave me a children’s book written in Spanish to share with my children; however, when I arrived back home, the book was missing, probably inadvertently left on the kitchen table.
Plate 4. Music and dancing at a Hispanic festival.
Data Analysis

The transcribed interviews were evaluated for quality using Kvale's (1996) criteria prior to analysis. This evaluation is presented in Chapter 5. The process of data analysis initially was designed to be concurrent. Due to multiple problems with receiving transcriptions, data analysis began when all data were collected. Quality of the study was evaluated using Stewart's (1998) criteria of veracity, objectivity, and perspicacity and is discussed in more detail in Chapter 5.

Prior to entry into the database, the transcriptions were read twice, once while listening to the audiotape recording. This process provided an opportunity to check the quality of the transcription and to attempt to fill in missing pieces of the interview. Due to extraneous noise, some data were irretrievable from the tapes.

Question Analysis

The interviews were guided by the Semistructured Interview Guide. Using the explanatory model design, questions regarding the symptom experience were asked. Other questions were designed to extract information regarding specific issues surrounding the symptom event such as emergency room experience, use of alternative healers, and changes to the healthcare system. Morse and Field (1995) described the process of question analysis as an analysis of each question rather than as an overall essence of the total experience. They suggested that this approach is appropriate for data analysis when a Semistructured Interview Guide is used. Examining the content of each question allowed for more detailed analysis and provided the “pieces” necessary for developing an understanding of the illness
representation and its management. Using this method allowed me to develop a systematic approach to analysis of each part of the interview as well as easier development of a coding scheme for each concept addressed by the questions in the Semistructured Interview Guide.

Coding

Coding data was structured prior to analysis and was guided by the questions in the Semistructured Interview Guide. Data bits consisted of phrases. The coding scheme was divided into two phases. The first phase of coding was based on questions from the Modified Interview Guide. These codes included emergency room, changes to the healthcare system, alternative healers, over-the-counter medications, home remedies, ethnicity, and common problems. This section of coding expanded as interviews were analyzed to include family, spirituality, compassion, and cost. Ultimately, alternative healers, over-the-counter medications, and home remedies were collapsed into a code labeled “self-care,” with “cause” emerging from the data as a new category.

The constructs of the Common Sense Model with regard to illness representation guided the second phase of coding. Data were coded for the subconstructs of representation: (a) identity, (b) cause, (c) time line, (d) control, and (e) consequences.
Pattern Analysis and Thematic Identification

The next level of analysis was the identification of patterns. The pattern that emerged from the data was the way in which the participants' most detailed symptom experiences were told. The thick description of the symptom experience surfaced, not when participants were asked to talk about a symptom episode of their choice, but when the participants were asked about using the emergency room or how they would change the healthcare system.

The final phase of data analysis was identifying the themes. As I became more immersed in the data, codes were added, patterns emerged, and a theme materialized. Cost emerged as the overall theme that permeated all of the participants' symptom experiences. The results are presented in Chapter 4, and a discussion follows in Chapter 5.

Data Management

Data were managed with the use of a computer program specifically designed for qualitative data management. QSR NUD*IST4© (1997) was used to organize, code, and search the database for common patterns and themes. Data from interviews, literature/document summaries, participant observations, and field notes were used in the overall analysis of data.

Data were stored in locked file cabinets that only I could access. Binders were used to organize photographs, flyers, reports, and other documents obtained during data collection.
Ethical Considerations

The Mexicana/o population is perceived by some as being vulnerable. Because some vulnerable populations are disenfranchised, there is a need for researchers to understand their roles in society, their issues, and their problems and concerns as well as to identify their strengths—which often are culturally based.

Approval for this program of research was obtained through the Institutional Review Board at the University of Utah. Recommendations offered by the board were incorporated into this study, and subsequent amendments to the initial research proposal were submitted through the appropriate channels for approval. Amendments for the Modified Interview Guide, expanding community boundaries, and including a monetary incentive were approved.

Written informed consent (see Appendixes G and H) was obtained from each study participant with an understanding of the voluntary nature of their participation. Special attention was given to ensure that those participants who could not read or spoke Spanish only had a full understanding of the meaning of their participation and the voluntary nature of that participation. The consent was discussed with them in Spanish, and all questions regarding the study and their participation were answered in Spanish prior to proceeding with the actual interview. Each participant was assured that there were no consequences for nonparticipation or stopping the interview at any time. Risks (minor emotional distress from recalling an illness experience) and benefits (contributing to the health of their community and increasing provider cultural competence) were
explained. An additional written permission to photograph was obtained. Anonymity was ensured by using pseudonyms when sharing the participants’ stories.

Questions from participants about what to do for specific healthcare problems were addressed at the end of each interview. All questions were answered; on occasion, however, participants were referred back to their primary care clinic for further information.

**Summary**

Ethnography is the process of uncovering the participants’ (emic) perspectives of the phenomenon being studied. Interviews were conducted in one way only in order to reveal this perspective. Westby (1990) stated that the researcher must ask the right question in the right way to the right people. Participants’ stories are painted onto the community portrait in order to provide a meanings-in-context presentation of the phenomenon that is the focus of the research. The use of ethnographic inquiry to explicate the symptom experience was an appropriate approach for the study of Mexicana/o symptom interpretation and management.
CHAPTER 4

RESULTS

La Cebolla

Neruda (1994) described the onion as complex and beautiful, a food of the common people. This ethnographic study was visualized metaphorically as an onion with multiple layers, each of which was peeled away to reveal the symptom interpretation and management experience of the participants who were at the heart of the onion. Each layer of the onion provided contextual grounding for the symptom experience. Thus, the results are presented in two parts. In Part 1, the outer layers of the onion are described, beginning with a broad historical perspective and concluding with a detailed description of the community where the participants live. As these outer layers are peeled away, the portrait over which the symptom experiences lie becomes more detailed. In Part 2, the participants' stories of symptom experience, which lie at the heart of the onion, are described.

Part 1: The Outer Layers

Included in this process of peeling away the layers of the onion are historical factors that influenced Mexicana/os in the United States and specifically in Utah, a discussion of cultural concepts such as family and spirituality and issues surrounding cultural identity. An introduction to the community and its available
services also are provided.

**History of Mexicana/os in the United States**

Prior to 1846 and the onset of the Mexican American War, much of the southwestern United States was Mexican territory. Although sparsely populated, many families lived in California, Nevada, Utah, Colorado, Arizona, New Mexico, and southwestern Texas (Meier & Ribera, 1993). These families were separated from the heartland of Mexico and, thus, developed their own unique culture. Political conflict between the motherland and her northern most territory created a climate of vulnerability that opened the door to Anglo conquest. The Mexican American War culminated in the Treaty of Guadalupe Hidalgo in 1848 in which Mexico lost its land north of the Rio Grande. Landowners were guaranteed rights; however, their lack of understanding of the Anglo political system and its laws created an environment in which they became “foreigners in their own land” (Meier & Ribera, 1993, p. 69). With the Gadsen Purchase in 1853, the division between Mexico and the United States was complete. Families were divided, particularly near the border. Anglos were scrutinizing the Mexican people. Their native language, customs, and religion were criticized as being “foreign.” The Anglos, leaving the Mexican people on the “outside” of this new society, were creating the norms.

Instances of racial hatred occurred in certain parts of the country where there was a greater concentration of Mexicana/os. In Texas, these “foreigners” were hunted by the Ku Klux Klan. In 1943, in Los Angeles, Mexicans were sought
out by servicemen and beaten, sometimes killed. This activity was looked upon as assistive to law enforcement. The perpetrators were seldom brought to justice (Meier & Ribera, 1993).

Interestingly, the Anglo landowners, ranchers, and agriculturists recognized a source of inexpensive labor in a people who did not understand the economics of business in the United States. Velez-Ibanez (1997) described this process of using Mexican labor as the commoditization of a people, a people who now thought of themselves as being “con un pie en cada lado” (born with one foot on each side of the border). Anglo men who had filled agricultural jobs went off to war, leaving these industries with a desperate need for laborers. Programs were created, whether formal like the Bracero program or informal like the “coyotes” smuggling truckloads of Mexicans across the border. However, once the war was over and Anglo men returned home needing jobs, the Mexican people were again displaced. Government money was spent to “deport” these workers back to Mexico. American citizens often were deported based simply on the color of their skin or the language they spoke. In the film Mi Familia (Thomas & Nava, 1995), there is a poignant depiction of this type of activity when a married and pregnant woman is rounded up on her way home from the market, put on a train, and taken to central Mexico. It took her 2 years to return to her family and her homeland. This historical perspective is captured by Anaya (1992) in Albuquerque:

Remember that onion when you think of our history, they promised not to take it, but they stripped it away, layer by layer, until all we have left is what you see here. El corazon, the core of the onion. They can’t strip the heart, it’s all we have left. (p. 173)
Today, persons of Mexican heritage constitute the largest minority group in the United States. Their numbers are increasing rapidly and are reported inaccurately in census data due to many errors in data collection and the fear of deportation. This group consists of families whose ancestors lived in the United States before Mexican cession, American citizens (persons of Mexican heritage born in the United States), and recent immigrants. This diversity within the Mexicano population creates its own complex web of issues.

According to a number of key informants, the issues facing each of these subgroups (Anglos refer to as Mexicans) can be quite different. The needs of Mexican Americans may be different from those of newly immigrated Mexicana/os or those Mexicana/os in the United States illegally. The U.S. Bureau of the Census (2000) made a concerted effort to ensure that ethnic minorities were counted. However, the census is being met with mixed reactions from the minority communities. There is some concern about the “dilution” of minority status and, therefore, a potential for decreased recognition of the number of minority persons residing in the United States (Schevitz, 2000). At one Mexicana/o celebration, a booth was set up to address the census issue specifically. The key informant at this booth spent time with me reviewing the forms, explaining the goal of the multiple choices, and ensuring that each person was counted. I asked if she believed that the complexity of the new system would serve as a barrier. She stated that the data collectors were trained to assist persons with completing the forms and intimated that the complexity would not be a barrier. In the area for which she was
responsible, the data collectors were bilingual, and they were knocking on every door.

History of Mexicana/os in Utah

In Utah, the history of Mexicana/os is one of a slightly different journey. Although Utah was part of Mexican territory, it was not highly populated by Mexicana/os. The arrival of Mexicana/os in any numbers is actually a late development in the history of the state that occurred well after the arrival of the Mormon pioneers in 1847. I reviewed Utah history as it is taught in the Salt Lake City School District. Two history textbooks reported a sketchy history of events involving Spanish priests trying to convert Native Americans prior to the arrival of the Mormon pioneers. The texts begin the “real” history of Utah with the arrival of the Mormon pioneers in 1847 (Holzapfel, 1999; McCormick, 1997). Few references are made to persons of Latina/o heritage.

Due to the paucity of ethnic recognition in the district textbooks, members of ethnic communities in Utah were asked to make a contribution regarding their part in Utah history. The history of Latina/os in Utah is divided into four historical phases: (a) the Spanish Period (to 1820), (b) the Mexican Period (1821 to 1900), (c) the Spanish-speaking People in Utah Period (1901 to 1930), and (d) the Spanish-speaking People in Utah Period (1930 to the present) (Mayer, 1975). The Spanish Period was one of exploration. The Mexican Period began with Mexican independence from Spain. The most historic event during this period was the signing of the Treaty of Guadalupe Hildalgo in 1848, which occurred after the
Mexican American War in which the United States laid claim to all land north of the Rio Grande.

In the early part of the 20th century, Mexican migration to Utah came in waves. This migration began in 1910 when job opportunities created an environment in which the Mexican people saw hope of improving their lot in life (Spanish-speaking People in Utah Period, 1901 to 1930). When the Great Depression hit Anglos, Mexicans were displaced from their jobs, torn from their families, and “shipped back home.” Prior to 1930, Mexicans worked for the railroad, the mines, and agriculture. Initially, many of these “immigrants” were single men who had married Indian and Anglo women. Entire families eventually migrated to the region, which allowed for the formation of Mexican communities. This community development created an environment in which Mexicana/os and other Latina/os could come together to maintain their cultural heritage as well as to provide unity when trying to confront issues of import to themselves and to their communities (Spanish-speaking People in Utah Period, 1931 to present).

Cultural Identity

Hispanic, Latino, Mexican, Mexican American, Chicano, La Raza, Mestizo, wetback, and Mojado are all labels that have been applied to persons of Mexican heritage at one time or another. What do they mean?

The term Hispanic was coined by the U.S. Bureau of the Census (2000) as a way to describe persons of Spanish origin and language. This term is used extensively in the literature. In addition, Hispanic has been used to encompass a
diverse population. However, the U.S. Bureau of the Census is effecting a change, with choices to include (a) no, not Spanish/Hispanic/Latino; (b) yes, Mexican/Mexican American/Chicano; (c) yes, Puerto Rican; (d) yes, Cuban; or (e) yes, other Spanish/Hispanic/Latino. A specific ethnicity or combination can be selected that is expected to reflect more closely her or his heritage, thus, the diversity of the population in the United States. The term Latino also is used as a general term when describing the diverse population of people more commonly referred to as Hispanic. Although this term is used interchangeably with Hispanic, some Latina/o leaders have argued that it more accurately reflects persons from Central America and South America. The term Mexican has many meanings; to some it is used to refer to anyone who looks remotely dark in coloration, but not black. One participant who was born and raised in the United States proudly stated that she was a Mexican because her parents were from Mexico. Yet, another participant, who had arrived in the study area 2 years ago from Mexico, did not like to be called Mexican because she believed it meant “dirty and lazy.” Mexican American is a term commonly used to refer to persons born in the United States of Mexican parentage. Chicano is a name born of the Movimiento of the 1960s, a group of Mexicans who had sociopolitical goals. La Raza is a term that refers to Mexican culture, whereas Mestizo has roots during the time of the Spanish conquest of Mexico when persons of mixed heritage (Indian and Mexican) were looked upon as inferior. A derogatory label used in the United States by Anglos is wetback, which refers to persons crossing the Rio Grande, carrying their clothes
on their backs or atop their heads to keep them dry, searching for work. *Mojado*, the Spanish term for wetback, is sometimes used by Mexicans to refer to each other in a somewhat derogatory manner.

One key informant summarized this complexity of labels. In her family, all of whom were born in the United States, multiple references are made to their heritage. Her mother refers to herself as Spanish, her older sister calls herself Mexican, she refers to herself as a Chicana, and her younger brother calls himself a Mexican American. The question is: Is there one label that fits everyone? Probably not, and as one key informant stated, “Why should there be?” From this overview of cultural identity, it is apparent that this is a complex issue, one that must be acknowledged by clinicians in an attempt to create an environment of cultural sensitivity.

*La Familia*

The concept of family being central to Mexican culture presents itself as remarkably complex (Caudle, 1993). The literature is infused with the concept of family as the central core of daily interactions, appearing to an outsider as “blood is thicker than water.” However, the literature and study participants present a picture that is confusing to an outsider such as myself.

In the movies *The Milagro Beanfield War* (Esparza & Redford, 1988) and *Mi Familia* (Thomas & Nava, 1995), much turmoil occurred within the families. The main character in *The Milagro Beanfield War*, despite objections by family and close friends, decided to take on the Anglo establishment, even shooting a patriarch
of the community. However, in the end, the Mexican community banded together to conquer the outsiders, who were trying to change their small village and, thus, supported the importance of family—nuclear and extended. Similarly, in *La Familia*, the *jefe* and *jefita* of the family live in great tumult. As their story unfolds, they survive the killing of their son by local police and the incarceration of their youngest son. Yet, another son becomes Anglicized and disowns his family. They experience great pride when a daughter becomes a nun only to be disgraced when she leaves her order and marries a priest. At the end of the film, however, they sit side by side at their dining-room table, surrounded by the empty chairs of their departed children and grandchildren, and conclude, “We were lucky. We have had a good life.”

This phenomenon, a sense of tension between positive and negative, old and new, also is apparent in the writings of Rudolfo Anaya, a well-known Chicano writer who weaves stories about life in *Nuevo Mexico*. His characters, Antonio (*Bless Me, Ultima* [1972]), Sonny Baca (*Shaman Winter* [1999]), Abran (*Albuquerque* [1992]), and Tortuga (*Tortuga* [1979]), all tell their stories of struggle and triumph interwoven into the fabric of complex family structures and activities. In each of these novels, the main character is a male struggling to make sense of his place in the world, his role in the family. Each of them takes a journey of the soul to find his ultimate destiny as a member of *La Raza*. Chavez (1994) in *Face of An Angel* tells the story of Sovieda, a young woman who journeys through life struggling to find her cultural identity and to make sense of
her family life, never once losing sight of her family as the core of her existence, even when they seemed to betray her. Each of these writers weaves stories that are rich in Mexican tradition; however, the tension buried within this complexity creates both cohesion and change in the family. This phenomenon is present in each of the stories.

This complexity, with its underlying tension, was reflected in the participants’ stories as well. One participant, when asked about her marital status, wove a complicated story of separation and widowhood, describing in graphic detail the electrocution death of her husband from whom she was separated. Yet, she took her children, who were small, to observe his burned and deformed body being removed from a tree. She concluded her story by saying, “I loved him, but he went with other women. Why did I take the children to see that?” This same participant’s story crossed four generations as she described the care of her mother, herself, her own children, and her grandchildren. She is both assisted by and turned away by her family, sacrificing her health to care for them. Yet, she talked with great pride about them and how they all work together. Although this participant’s story was the most dramatic, the theme of family tension repeated itself over and over. Whether literary characters or study participants, the tension between old and new, male and female, Mexicano and Anglo was present, almost as an implicit source of strength.

Family relationships extend over generations as well as outside the family in a system called compadrazgo. This is a complex system of kinship that is best
described as coparenting. *Compadres* provide for extended support within the family structure. Most important of these are the *compadres* who serve as baptismal sponsors, followed by those who serve as confirmation sponsors. The *compadres* are treated with the same respect as one's own parents and grandparents. *Compadres* are often blood relatives who serve to strengthen the family bonds but who also may be friends whom one simply “hangs out” with.

Community

In Mexicana/o culture, there is a strong sense that family and community are more important than the individual. Sonny Baca, the main character in Anaya's (1999) *Shaman Winter*, sacrifices himself in order to save his family and in turn his community. Despite objections from his lover and family, he feels compelled to use his ability to visit the dream world to save his people even though his physical, mental, and spiritual survival is at great risk. He is looked upon as a hero. A similar situation occurs in *The Milagro Beanfield War* (Esparza & Redford, 1988), when the main character takes on the Anglo establishment in order to save his community, even though he may lose his family. His commitment to community finally is recognized by his people who then band together to “beat” the establishment. This commitment to community over self often is misunderstood in Anglo society where “rugged individualism” is looked upon as the primary accepted societal behavior. This cultural clash creates a tension between the Mexicana/o and Anglo cultures. This sense of community was apparent at each of the festivals I attended. The energy was palpable, people came with their entire
family, and there was always music and food (see Plate 5). There was a sense of community and pride that even I, as an Anglo outsider, could feel.

Time as Relative

Time in the Mexicana/o culture is relative. Mexicana/os perceive that in Anglo society there is an overreliance on watching the clock. This sense of time as different from that of Anglo expectations was apparent during one interview. I asked a female participant if she worked full time or part time. She said she did not know. She said that she worked 60 hours per week in order to provide for her family. I told her that in the United States 40 hours per week is considered working full time. She laughed and said, “I guess where I come from everyone works full time.” There was no sense of time in terms of counting minutes and hours; time was simply what it took to do what needed to be done. This difference in perception of time often is apparent in clinics trying to meet the needs of Mexicana/os. A common complaint in Anglo-run clinics (in my experience as a clinician) is that the Mexicana/o patients “never show up on time” for their appointments, which creates a conflict between the clinical setting and the patient. The norm for the Mexicana/o patient is going to a clinic for service and waiting for long periods of time to be seen. He or she is less likely to complain about waiting to be seen than are Anglo counterparts. During the study, I found this sense of time to be challenging. As an Anglo, I have a sense of time that was different from the participants. I made appointments for specific times and found that the participants were always surprised to see me at that scheduled time. Each
Plate 5. Dillon eating authentic food at a festival.
of the events I attended that were not governed by Anglos started “somewhere around” the time stated on the flyers. I found the lack of pressure about time to be a distinct relief from my usual lifestyle where everything is organized by the clock. I experienced a sense of not having to rush while interacting with the participants or persons at events. This sense of timelessness was not always the case when interacting with key informants, whether Latina/o or Anglo. It was as though the Latina/o key informants had been “acculturated,” becoming more Anglo-like when functioning in their positions of authority.

**Mind, Body, and Spirit**

The concept of a mind, body, and spirit connection is central to Mexicana/o culture. As in the United States, there is no separation or reductionistic approach to illness or health. Anzaldua (1987) addressed this issue of Anglo dominance in trying to separate the mind from the body and spirit of her people. As a Chicana feminist lesbian writer, she discussed this separation being forced on her people as a way to control them. She wrote about the strength that comes from recognizing this connectedness in her people, which goes back to “the beginning,” to the people of Aztlan—the Aztecs. This connectedness also is seen in the writings of Anaya (1972, 1979, 1992, 1999). In *Tortuga* (Anaya, 1979), a boy is paralyzed and sent to an Anglo hospital far from home where the doctors try to heal his body. A Mexicana nurse helps him to find the connection between his mind, body, and spirit, which is what eventually leads to his healing and return home.
A participant who told of a daughter who had seizures shared an example of this connectedness. She stated that her daughter had seizures, but no one could tell her why. She used a barrida (ritual) to chase away the bad spirits that affected her daughter, and for long periods of time, she did not have a seizure. The participant also used an anticonvulsant medication prescribed by the doctors but believed that addressed only part of the problem. This participant recognized the connection between mind, body, and spirit in treating her daughter’s seizure disorder, something that the Anglo doctors “would not accept.”

Spirituality

A sense of spirituality exists strongly in the Mexicana/o culture. Two thirds of the study participants were Catholic, which is the primary religion practiced by Mexicana/os. Spirituality is a rich source of strength for this culture. Symbolism of spirituality is seen in everyday objects and icons. The Virgen de Guadalupe is a central figure, and daily prayers to the santos (saints) are common.

One example of spirituality was seen at a shrine in Salt Lake City where a tree branch was cut and the face of the Virgin Mother, who was “crying,” was seen. The city planned to remove the “crying virgin’s” face from the tree to decrease the congestion that occurred at the site. This decision was met with public outcry. The shrine exists today (see Plate 6). Candles burn constantly, and one can climb the stairs of the wooden platform to observe the phenomenon and to pray.

In Tortuga (Anaya, 1979), spirituality is described in terms of symbolism and a deep belief in the connectedness of this spirituality and daily life. Tortuga
Plate 6. Shrine of the crying virgin in Salt Lake City, Utah.
faces the adversity of total paralysis when he arrives at a hospital for children with paralyzing maladies such as those stricken with polio. He is placed in a body cast that covers his torso, leaving only his head, arms, and legs exposed, which is much like the shell of the turtle, gathering strength to get well from the spirit of the turtle-shaped mountain (seen from his hospital room window). In *Shaman Winter* (Anaya, 1999), Sonny Baca, also paralyzed, must try to understand the spiritual symbolism that he faces daily in order to triumph over evil. His battle against “Raven” (the character representing evil in the story) takes place at many levels, including both the dream world and the physical world. Spirituality connects the two worlds as well as the two men.

In summary, each of these concepts (*la familia*, community, time as relative, mind, body, and spirit, and spirituality) is basic to Mexicana/o culture. Although presented as part of the outer layers of the onion, these concepts lie at “the core of the onion. . . . You can’t strip that away. It will endure forever” (Anaya, 1992, p. 173). An understanding of these concepts as basic to Mexicana/o culture provides insight into the layers of the onion that surround the heart of the onion, the participants’ symptom experiences.

**Current Issues in Utah’s Latina/o Community**

Utah is an Anglo-dominated state that is run by a dominant religion, one in which the majority of Latina/os do not participate. This situation creates an environment for Latina/os that is somewhat foreign and exclusionary. In speaking with Latina/o leaders, the discourse is similar. There is diversity within the
Latina/o community, meaning that this group as a whole is made up of many nationalities in which language and education are barriers to advancement. Many Latina/o leaders find the diversity of the group to be challenging both internally and externally. The diversity of the group creates an internal environment that lacks cohesion in addressing Latina/o issues. To those outside the Latina/o community, there is a sense of a lack of unity. In response to this criticism, one key informant, a Latino leader, asked, “Why do we have to all be the same?”

One of the greatest challenges facing the Latina/o community is organizing themselves so that individual subgroup issues are addressed but not at the expense of the Latina/o community as a whole. A key informant described this challenge in relationship to Mexicana/os. He stated that although all Mexicana/os are Latina/o, there are different issues faced by Mexican Americans as well as recent Mexican immigrants. At times, agreement by the two groups on broad issues was challenging. Many programs such as the assistance offered by the Mexican Consulate are there to support transition and to create opportunities for Latina/os in Utah.

The Latina/o community comes together to face issues of major import. One example of “coming together” occurred in 1998 when law enforcement appealed to Attorney General Janet Reno for permission to deputize all officers of any law enforcement agency in Utah as Immigration and Naturalization Service agents. Law enforcement cited the “huge” increase in drug trafficking by illegal immigrants (south of the border) as one of Utah’s most serious crime issues. This
provision would have allowed any officer to approach someone they believed "suspicious" and demand papers proving his or her citizenship or legal right to be in the United States. In response to what appeared to some to be a reenactment of the treatment of Mexicanos during the years after the Great Depression when they were deported based on the color of their skin, the Latina/o community fought hard to have this issue quashed. Law enforcement responded by stating that what was being targeted was the Latina/o on Latina/o crime. Although the initiative was never enacted, the issue continued to be a point of discussion between law enforcement and Latina/o leaders. The Latina/o community is torn on this issue between Latina/os in law enforcement and Latina/os outside of law enforcement. This tension was depicted in The Milagro Beanfield War (Esparza & Redford, 1988), when a woman stated, "Why is it that when we are mad at them we only end up hurting each other?" Yet, in the end, the Mexicano community came together to defeat the Anglo encroachment on their land.

The West Side

The west side of Salt Lake City (comprised primarily of Glendale, Poplar Grove, and Rose Park) is a community of immigrants, and it has remained so for many generations. According to one key informant, there is a rich history of hard-working immigrants from many countries settling in this area. One reason for settling in this area is that the land was inexpensive. Another reason was the formation of a community of similar people, hard-working, honest people wanting to provide a home for their families. According to this same key informant, as the
diversity of the population changed, the Anglo Mormon community in the area was threatened that it would lose its base of power. Because of this perceived threat, in 1995, the west-side community was divided into separate communities, each being addressed by its own community council. The intent of this action was to dilute the Latina/o population in the community. The new boundaries creating the Glendale and Poplar Grove communities were analogous to the division created by the Treaty of Guadalupe Hildalgo. Families who were once united were now divided. Services for the communities were being examined as separate, often using community council boundaries to determine services. A politically active key informant described this division based on community council boundaries as “diluting” the strength of the cultural diversity within the community, which is now “perceived as two areas needing service rather than one. This often makes it more difficult to get what we need on the west side.” However, the people living day to day within these communities remain unaware of the political divisions that have been created, flowing freely from one community to the next, much like the border towns in the southwest United States.

Poplar Grove

Poplar Grove is a culturally diverse community, although the majority of its members are Latina/o. An Anglo man who moved to the area because of its diversity chairs the Poplar Grove Community Council. Continual attempts are made by the council to be inclusive; however, the organization remains almost exclusively Anglo. Latina/o representation is present only in the form of the Salt
Lake City Police community liaison. This key informant candidly discussed the issue of “Hispanic on Hispanic” crime that is being targeted in the area. However, an Anglo youth, who presented a report by the Department of Youth Services, provided statistics demonstrating a distinctly different picture: The majority of crime in the area is credited to Anglo perpetrators. This report was interesting, considering the “findings” of law enforcement.

Approximately 3,000 families live in Poplar Grove. North Temple Street borders Poplar Grove on the north, which is a business district with eateries, grocery stores, gas stations, the Fair Park, and city and county offices. To the south, Poplar Grove is bordered by railroad tracks, separating it from Jordan Park, which is the focus of much of the community council work. The east side of Poplar Grove is bordered by Interstate 15. On the west side, Redwood Road provides a border of industry (see Plate 7) and access. Public transportation is available, but it does not run on Sunday. Within the community boundaries are one chain grocery store, one family-run grocery store, two chain convenience stores, and a “mom-and-pop” convenience store (see Plate 8). There is also a chain pizza delivery service, a panaderia (see Plate 9), a Polynesian food store, a tortilla factory, and many Latina/o eating establishments. Within the Poplar Grove boundaries are a fire station, a senior center, an adult day care, a botanica, the Salvation Army, the Neighborhood House, and a Boys and Girls Club. There are three parks, a library, and several churches (one Catholic church—no masses in Spanish, one LDS church, one Tongan Methodist church, and one—now
Plate 7. A sign at a business in the industrial area.
defunct—Spanish Evangelical church). A number of hair salons and auto repair shops as well as two elementary schools and one private (Catholic) elementary school lie within the boundaries. This blending of old and new is visible throughout the neighborhood (see Plate 10).

Healthcare Services in Poplar Grove

Perspectives on the healthcare of the community are as diverse as its population. In discussions with the principals of the two elementary schools within the boundaries of Poplar Grove, responses were mixed. Both schools are not well funded, they have diverse populations, and they face similar issues on a daily basis. However, the way that each principal told her story of her respective school was colored by her personal experiences. One principal spoke as an Anglo outsider, describing successful networking and support from the Neighborhood Clinic. The other principal spoke as a woman who grew up Mexican in Utah and referred to herself as a Chicana. She vividly described an incident that she believed demonstrated the lack of support given to the area.

We were having a community meeting at the school. There were some gang members hanging out across the street. One of our families was getting out of their truck when they started calling them names. The father sent his family running into the school as the gang members crossed the street. They began chasing him around the building, hitting him with a bat. We called the police, grabbed the man as he ran by a door, and locked down the school. The police came. They acted like it was no big deal. Like, what’s one more Mexican. I was very angry.

Both of these principals discussed the issues their respective schools faced on a daily basis. However, the Chicana principal spoke with a passion for her people
Plate 10. An example of the old and new blending.
that was not readily apparent during the meeting with the Anglo principal.

Limited community-based healthcare services are available to the people of Poplar Grove, with multiple services available in Salt Lake City and the surrounding areas. At the farthest edge of its northwestern boundary is an InstaCare, an urgent care facility run by a regional health network. This clinic offers services from 8:00 a.m. to 10:00 p.m. 7 days a week. Access to primary care clinics is limited to the Northwest Community Health Clinic 11 blocks north of Poplar Grove’s northern boundary. This clinic offers services Monday through Friday from 8:00 a.m. to 5:00 p.m., with a plan to offer services in the evening (according to the clinic director). The Neighborhood Clinic (sponsored by the same regional health network that supports the InstaCare) is located four blocks south of the southern boundary of the community. This clinic is located in a community center, with operating hours Monday through Friday from 9:00 a.m. to 5:00 p.m. Each of these clinics stated its mission as “service to the community.” In November 1999, Centro de Salud Familiar opened its doors on Redwood Road between Sixth and Seventh South, offering bilingual healthcare services. According to the clinical director, the hours of operation vary, with some evening and weekend hours. At all four facilities, anyone is seen regardless of ability to pay; however, payment (or arrangements to pay) is expected at the time of service. One botanica (see Plate 11) offers the services of an herbalist as well as a brujo (male witch). Herbs, candles, statues, and talismans (see Plate 12) are sold in the botanica.
Plate II. Botanica in Poplar Grove.
Plate 12. Artifacts from Botanica.
Although these services were not within easy walking distance of the study area, these and other services in Salt Lake City were accessible by car or public transportation. Public transportation (i.e., bus) was not available after 10:00 p.m. or on Sundays. For most participants, cab fare was cost prohibitive. Only 5 of the participants had cars available to them during daytime hours. One key informant described how one family tried to access services.

Her husband has the car so he can get to and from work. She must take the baby and the little boy (2 years old) out even in bad weather to get the bus to go. I saw her standing at the bus stop in the snow waiting one day. It was pitiful. Then when she gets to the clinic late, they turn her away. So what good is it when they can’t just walk there?

The use of emergency services was mentioned as one source of healthcare. Present in the community is a city fire department, which is staffed 24 hours a day by paramedics. No emergency room or hospital services are available within the Poplar Grove community. However, these services are available 24 hours a day 7 days a week outside the community boundaries. Satisfaction with care given in these facilities was mixed. Emergency room personnel often were cited as experts in caring for any healthcare problem, but providers lacked sensitivity. These services were used more often due to expanded hours of operation.

One barrier to accessing services can be language. Services at the InstaCare are offered exclusively by physicians, none of whom speaks Spanish. Physicians, nurse practitioners, and physician assistants, many of whom are bilingual, offer services at the Northwest Community Health Clinic. The Northwest Community Health Clinic provides services by nurse practitioners who speak some Spanish. A
bilingual nurse practitioner/midwife and a part-time physician provide services at the Centro de Salud Familiar.

**Part 2: El Corazon de la Cebolla**
*(The Heart of the Onion)*

The multiple layers that provided the contextual grounding for this study were peeled away. Lying at the heart of this “food of the common people” were the participants and their symptom experiences. A description of the participants’ stories of symptom interpretation and management is presented. The data are presented in sections that address each of the research questions, which is consistent with Morse and Field’s (1995) question analysis as a method of data analysis.

**Most Common Problems**

In order to provide a framework for exploring the symptom experience, participants were asked about the most common problems they dealt with regarding their health or the health of family members. This question proved to pose some difficulties in extricating the stories of symptom interpretation and management. Most participants simply said “gripe” (cold/flu), and they did not seem to believe this was an important issue to discuss. When I probed for more information using Kleinman’s (1980) explanatory model, participants gave answers to direct questions. A majority of the participants chose to talk about their chronic illness experiences. However, when I asked about a recent trip to the emergency room or how they would change the healthcare system, participants shared stories rich in
detail about a variety of illness episodes. One participant (G.V.) stated that the entire family was “very healthy”; . . . [there were] no common problems.” However, when I asked about the use of the emergency room, she gave a detailed description of the multiple emergency room visits her husband had made over the past month prior to the interview. Two of the visits required the use of an ambulance, with the last trip resulting in emergency surgery.

Responses to this question about the most common problems were categorized into acute and chronic problems (see Table 3). Participants often named more than one problem. Infections were common for the participants, encompassing both viral and bacterial origins. One interesting differentiation of an acute problem was the description of *gripe* versus flu. Both were acute common illnesses, but flu was the more serious of the two, differentiated by higher fever and longer duration. In neither case did the participants believe these illnesses required a visit to a doctor or antibiotics. “They just go away.” The most common other acute problem discussed was pain originating from various body parts. Although participants tended to describe acute problems with symptom terms, a diagnostic label such as anemia, diabetes, or arthritis usually identified chronic problems. Thus, those with chronic problems tended to use a medical “disease” representation versus an “illness” representation.

**Representation**

The Common Sense Model was used as the guiding framework for the research questions. Considering Research Question 1 (What is the illness
Table 3

Common Problems

<table>
<thead>
<tr>
<th></th>
<th>Acute (n = 39)</th>
<th>Other (n = 8)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Infection (n = 31)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Bladder infection</td>
<td></td>
<td>Ear wax</td>
</tr>
<tr>
<td>Tooth abscess</td>
<td></td>
<td>Febrile seizure</td>
</tr>
<tr>
<td>H. pylori</td>
<td></td>
<td>Dehydration</td>
</tr>
<tr>
<td>Oral herpes</td>
<td></td>
<td>Vision loss</td>
</tr>
<tr>
<td>Flu</td>
<td></td>
<td>Kidney stone</td>
</tr>
<tr>
<td>Pink eye</td>
<td></td>
<td>Chest pain</td>
</tr>
<tr>
<td>Cold (gripe)</td>
<td></td>
<td>Pelvic pain</td>
</tr>
<tr>
<td>Pneumonia</td>
<td></td>
<td>Bladder tumor pain</td>
</tr>
<tr>
<td>Ear infection</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Strep throat</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Cough</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Fever</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Chronic (n = 19)

|                              |                                    |                           |
| Diabetes                     | Heart disease                       | Hypertension              |
| Anemia                       | Paralysis                           | Renal failure             |
| Obesity                      | Memory problems                     | Stomach problems          |
| Asthma                       | Seasonal allergies                  | Panic disorder            |
| Depression                   | Chronic back pain                   | Arthritis                 |
|                             | Extremity pain                      |                           |

Note. Participants discussed more than one problem.
representation?), the representation construct of the model is the initial phase when the participant formulates an idea of what he or she is dealing with (identity), what is causing it (cause), how long will it last (time line), how he or she deals with it (control), and what might happen if he or she does or does not act on the stimulus (consequences).

How the participant labeled or identified an illness episode guided the remainder of the healing process. Previous experience with the symptom provided the participant with a historical perspective from which to address the symptom interpretation and episode management. The following example, as told by S.M., demonstrates how this historical perspective influenced symptom interpretation and management: "He [her son] has had infections since he was a baby. We have been to the hospital with him so many times. I know that if his fever lasts more than 5 hours we must take him to the emergency room or he could die."

Many participants had diagnosis-type labels for the illness episode. One participant (Er.G.) talked in great detail about persistent crying and yelling at her children, alerting her to her problem with depression. "I couldn’t go anywhere, and I was home all day cleaning and cooking with all four kids and that was driving me nuts." Pain was a presenting symptom for many participants, which they attributed to multiple causes. Another participant talked about the smell of her son’s urine as a method for identifying bladder infection. Es.G., another participant, discovered a blackened toe while in the shower, which she identified as an injury (later proved to be a diabetic infection in the toe) for which she sought
help. Es.G. stated:

I looked down at my toe and it was black. I knew it was broken, so I went to see my doctor. He told me I had gangrene and sent me to the emergency room. The doctor there told me it was an infection because of my diabetes. I got [points to vein in arm] the medicine here even at home. I knew it was broken.

Participants often simply stated the diagnosis for the problem such as pneumonia, diabetes, *gripe*, or depression (see Table 3).

All participants were able to tell what they believed was the cause of the particular illness episode they chose to discuss. Many of the responses were straightforward, whereas others were more vague. Findings regarding the cause of the illness episode are presented in Table 4. Participants identified a direct cause and effect between the symptom and its cause; however, some participants mentioned causes that had no scientific relationship to the symptom episode they discussed. G.P. talked about her husband’s back and leg pain, which she attributed to acid that had spilled on his pants while at work and had dried there. He had not burned his leg. Yet another participant (A.M.) described the cause of her back pain as the “burned thyroids” she had had (inferred radiation of the thyroid). G.V. attributed an abnormal pap smear to a lack of cleanliness. The most common cause of *gripe* was attributed to a change in the weather.

How long a symptom lasted influenced how participants reacted to the symptom itself. When discussing cold/flu (*gripe*) symptoms, many participants stated that the symptoms would last from 2 to 7 days. In contrast, those participants who discussed chronic illnesses identified a time line of “the rest of
Table 4

*Causes of Symptom and Illness Episode*

<table>
<thead>
<tr>
<th>Scientific basis</th>
<th>Folk origin</th>
</tr>
</thead>
<tbody>
<tr>
<td>Foreign bodies</td>
<td>Weather</td>
</tr>
<tr>
<td>Isolation</td>
<td>“Burned” thyroids</td>
</tr>
<tr>
<td>Germs (viral and bacterial)</td>
<td>Acid spill on pants</td>
</tr>
<tr>
<td>Heredity</td>
<td>Size of the child</td>
</tr>
<tr>
<td>Lack of exercise</td>
<td>Drinking too much juice</td>
</tr>
<tr>
<td>Bubble baths</td>
<td>Lack of cleanliness</td>
</tr>
<tr>
<td>Elevated blood sugar</td>
<td></td>
</tr>
<tr>
<td>Allergic reaction</td>
<td></td>
</tr>
<tr>
<td>Poor eating habits</td>
<td></td>
</tr>
<tr>
<td>Irritant foods</td>
<td></td>
</tr>
<tr>
<td>Pollution</td>
<td></td>
</tr>
<tr>
<td>Menses</td>
<td></td>
</tr>
<tr>
<td>Not drinking enough water</td>
<td></td>
</tr>
<tr>
<td>Congenital birth defect</td>
<td></td>
</tr>
<tr>
<td>Not wiping after going to bathroom</td>
<td></td>
</tr>
</tbody>
</table>

my life.” When discussing her child’s long history of bladder infections, one participant (S.M.) described a 5-hour time line for responding to the fever. If the fever was still present, she would change her action plan. Two participants (J.T. and G.V.) described immediate responses to pain; one caused by a grease burn required immediate application of a wet towel and the other caused by abdominal pain precipitated a call to 9-1-1. Two participants (J.T.J. and A.C.) described chronic ear infections in their children that had “been there since birth,” suggesting
a lifelong problem. Diabetes also was presented with a similar time line by 3 participants (S.D., J.T.J., and Es.G.). They stated that they knew they would have the disease for “their whole lives” or “until they find a cure.”

Control over the symptom can be interpreted to be a simple yes or no response. In other words, did the participants believe they could control the symptom? All participants stated that they could control the symptom and went on to identify ways of controlling symptoms, including simple observation, use of over-the-counter medications or home remedies, alternative therapies, and use of the conventional healthcare system. Ways of controlling symptoms are presented in more detail when discussing specific ways of coping with the symptom experience.

Responses from the participants regarding consequences focused on negative outcomes if they failed to respond to the symptom episode. These responses varied such as worsening pain, losing vision, “going nuts,” hearing loss, unconsciousness, continued obesity, worsening heartburn, loss of body parts, renal transplantation, and death. Several participants stated that a failure to respond would result in having to seek help within the conventional healthcare system, but it “would be expensive.” Even though the participants focused on negative outcomes, “it just went away” was mentioned when symptoms such as gripe were discussed.

Symptom Management

Considering Research Question 2 (How are these symptoms managed?) leads to a discussion of how participants dealt with each symptom experience. Continuing to use the Common Sense Model as a guiding framework, I present the
constructs of coping and appraisal.

This phase of illness representation (coping) suggests action on the parts of the participants. How the participants coped depended on the gravity of the illness, availability of services, or their ability to pay for services. Four categories of the types of coping emerged from the data: (a) over-the-counter medications, (b) home remedies, (c) alternative therapies, and (d) conventional healthcare. A summary of the types of coping is presented in Table 5. One participant (M.G.) described (as paraphrased by me) the following barrida (ritual) she learned from the curanderas in the borderlands of Texas as a method of coping with multiple childhood ills.

I know how to do the eggs now. You take a raw egg, and it has to be at night. My daughter lays on the bed, and I pass the egg over her in the shape of the sign of the cross. You have to say “Our Fathers” and “Hail Marys” nine times while you keep moving the egg. Then you put the egg in a cup of water by the bed for 3 days. Before the sun rises on the 3rd day, you throw the egg into the toilet where the water runs like the river. For those 3 days, it has to be very near the baby or child. But sometimes the egg can get really rotten, so then I just repeat the same thing for 3 days in a row. I have used this for the baby crying and when my daughter has had a fever. It covers a lot of things. That’s a tradition with us in Texas, and I do it here [Utah].

This participant used the barrida learned from a curandera as a home remedy, but she stated that “you must believe it will work.” Two other participants reported seeking the services of curanderas on the recommendations of family members. One participant (E.G.) sought help for a rash on her skin; lemons squeezed and rubbed on the rash were recommended. E.G. stated that she did not believe in “that kind of thing” and did not try the treatment. Another participant (L.G.) went on her husband’s recommendation for facial paralysis. The use of brown tree bark
Table 5

*Coping*

<table>
<thead>
<tr>
<th>Over-the-counter medication</th>
<th>Home remedies</th>
</tr>
</thead>
<tbody>
<tr>
<td>Tylenol</td>
<td>Chest poultices</td>
</tr>
<tr>
<td>Advil</td>
<td>Bed rest</td>
</tr>
<tr>
<td>Aspirin</td>
<td>Juices</td>
</tr>
<tr>
<td>Benadryl</td>
<td>Soups</td>
</tr>
<tr>
<td>Robitussin</td>
<td>Honey</td>
</tr>
<tr>
<td>Ricola</td>
<td></td>
</tr>
<tr>
<td>Vitamins</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Alternative therapies</th>
<th>Conventional healthcare</th>
</tr>
</thead>
<tbody>
<tr>
<td>Chiropractor</td>
<td>Chronic prescription medication</td>
</tr>
<tr>
<td>Herbs</td>
<td>Antibiotics</td>
</tr>
<tr>
<td>—Chamomile, olive oil</td>
<td></td>
</tr>
<tr>
<td>—St. John’s Wort</td>
<td></td>
</tr>
<tr>
<td><em>Curandera</em></td>
<td>Pain medication</td>
</tr>
<tr>
<td>—Lemon peel application</td>
<td></td>
</tr>
<tr>
<td>—Tree bark tea</td>
<td></td>
</tr>
<tr>
<td>Self-performed <em>barrida</em> (a folk medicine ritual)</td>
<td>Visit to the clinic</td>
</tr>
<tr>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Using over-the-counter medications was the most common coping modality described by all participants. One participant started singing when describing the use of “Ricola” (a brand name cough preparation that is advertised on television by
actors singing out the name of the product) for the treatment of cough. Using home remedies also was common. One participant described the use of honey as an application for a severe burn, whereas others described using juices and bed rest to treat common ailments. Entry into the conventional healthcare system as a method of coping was most common for participants who had chronic illnesses such as diabetes \( (n = 3) \) and those with acute pain \( (n = 4) \).

In this phase, the participant asks whether or not the method of coping is effective. This phase can occur quite rapidly after the onset of the illness episode, depending on the severity of the symptom or its perceived severity. This phase of illness representation ties in with perceived consequences. Four patterns of appraisal emerged from the participants’ responses: (a) self-care → worked, (b) conventional healthcare → worked, (c) self-care → did not work → conventional healthcare, and (d) conventional healthcare → did not work → self-care. These patterns are presented with supporting data in Table 6. Participants stated that their decisions to initiate treatment and reappraisal were based upon how much services would cost. One participant stated that without insurance she would not have gone to the clinic for services; rather, she would have waited to see if she got any sicker. The cost of healthcare services emerged repeatedly from the data.

**Exemplar Cases of Illness Representation**

Three cases were selected as exemplars in terms of describing the complex process of illness representation. Each of these cases demonstrates the process in its own unique way.
Table 6

*Four Patterns of Appraisal*

<table>
<thead>
<tr>
<th>Pattern</th>
<th>Quote</th>
</tr>
</thead>
<tbody>
<tr>
<td>Self-care → worked</td>
<td>“I just gave her Tylenol. She got better.” (S.D.)</td>
</tr>
<tr>
<td>Conventional healthcare → worked</td>
<td>“I took him to the emergency room and they found the tumor. He’s okay now.” (G.V.)</td>
</tr>
<tr>
<td>Self-care → did not work → conventional healthcare</td>
<td>“I tried the towel on my head and laid down to rest. My eyes did not get better. My wife drove me to the emergency room. They gave me stuff in the IV [intravenous] and I got better.” (J.T.J.)</td>
</tr>
<tr>
<td>Conventional healthcare → did not work → self-care</td>
<td>“They said it was the wax in her ears. They gave me the medicine, but it didn’t help her. I called my mom in California. She does things with herbs you know. She told me to put the oil in her ears and then cotton. It really worked.” (A.C.)</td>
</tr>
</tbody>
</table>

The first case presents the story of E.B., which was told in Spanish (the translation is presented). This case provides a clever approach to addressing the symptom experience.

I had a bad tooth. It was caused by dental floss getting caught in my teeth. I tried to get an appointment with my clinic, but they couldn’t see me for a long time. I tried to wait. Then it began to swell around my eye. I knew this was serious. I tried again to get an appointment at my clinic. They told me I would have to wait. I had heard about a free clinic. I dressed up like a homeless person and went to the shelter clinic. They saw me right away, gave me Ampicillin, and I got better very fast. I even had a bubble [E.B. lifts her lip to show the affected area on her gum] there that drained pus.
They took good care of me. I knew I needed help because it was so close to my eye. [E.B. very animatedly demonstrated how swollen her face had become and how the whole problem had affected her speech. She apologized for solving her problem by going to the homeless shelter but stated it was the only way she could think of to solve her problem.]

The second case demonstrates a more emotional response to the symptom experience. J.T. spoke rapidly while telling this experience, becoming very animated, almost as if she was reliving it.

Our apartment was very small. I was holding the baby while I was cooking the breakfast. The lard had melted and was cooking in the pan. I went to the bathroom, and when I returned, the pan was on fire. I laid the baby down and grabbed the pan. The hot grease splashed onto my hand and arm. It looked like my skin was melting off. I ran to the bathroom [it was only a few feet away] to get a wet towel. I forgot about the baby. I ran back thinking that the fire would spread and get the baby. I got the fire out. My arm was melting. I grabbed the baby and ran across the street to a woman’s house. She looked at my arm and poured honey on it. I threw the baby on her bed and ran out of her house. I got in a cab. There were no ambulances then. The cab took me to the emergency room. I can’t even remember if I paid him. They took care of my arm. They gave me pain medicine. They wanted to put me in the hospital. I couldn’t stay. If I wasn’t home when my husband got home, with his breakfast ready, he would beat me. I had to leave. A cab took me home. I don’t know if I paid him either. I was in so much pain. My husband did not come home until the next day at 2:00 in the afternoon. He beat me anyway.

Another participant (I.A.) told her story of a symptom experience with an episode of chest pain. Her story of the experience was difficult to follow.

I was coming home from work with a friend. I started getting chest pain. I figured it was an allergic reaction to some medication I had taken. My friend wanted to take me to the closest hospital, but I said, “No, don’t take me to Death Valley.” I thought I was going to pass out. I made her take me home. As soon as I got home, I took a Benadryl and called my daughter. I thought I was going to die. I
was going to call an ambulance, then tried to wait for my daughter. Then the pain got worse. I got really scared that I might die right there. So I called 9-1-1. I left my door open so I would not have to get up to let them in. I was so sick. I didn’t think I would make it. I heard the ambulance at the security gate, but I was too weak to buzz them in. [Now I.A. starts discussing the risks and benefits of a locked security gate and looks at me asking how I got in. Surprised that I walked through an open gate, she continued her story. She called out to a neighbor through her open doorway to open the gate.] The paramedics got there the same time as my daughter. They put oxygen on me and told me I needed to go to the hospital. I thought it was probably a good idea. They said I would have to walk down the stairs to get on their stretcher. I told them my daughter could drive me. They could be ready to help an old person who really needed it. I got in my daughter’s car, and she took me to the hospital.

Each of these detailed symptom experiences provides insight into the complexity as well as the similarity of the process of the symptom experience regardless of the symptom, the person experiencing the symptom, or the person’s reaction to the symptom.

Use of Healthcare Resources

Healthcare system issues that might influence the symptom experience were explored. Questions about the use of the emergency room and how the participant would change the healthcare system were explored with the participants. Issues of compassion and cost of healthcare emerged from this question analysis. Answers to these questions assisted me in exploring the “why” research question of illness representation and management.

Participants were asked why they would use emergency room services. Reasons for this use included broken bones, lacerations, pain, seizures, trouble
breathing, chest pain, and high and persistent fever (especially in children). Two other reasons for using the emergency room for nonurgent problems were lack of "timely" appointments at their primary care clinic and their clinic not being open.

When I asked how they would change the healthcare system, most participants were surprised. They stated that no one had ever asked them what they thought about it. Four patterns for change emerged from the data: (a) decrease cost, (b) decrease waiting time, (c) increase compassion, and (d) increase hours of availability. These patterns with supporting data are presented in Table 7. All of the participants voiced satisfaction with their primary care providers once they could see them. Primary care clinics providing service to Poplar Grove residents reported plans to address the issues of long waiting times and increasing hours of availability.

**Thematic Analysis**

Three key patterns emerged from the data relating to compassion, access to care, and cost of healthcare services. Participants passionately discussed the issues of compassion and access to care, whereas cost was discussed most often with a sense of detachment.

As an issue, compassion or lack of compassion emerged from the data, most often directly related to a participant's interaction with the conventional healthcare system. Three participants stated that they were "treated well," whereas the remaining 15 participants shared stories about varying degrees of a lack of compassion when using conventional healthcare services.
### Table 7

**Patterns for Suggested Changes in the Healthcare System**

<table>
<thead>
<tr>
<th>Pattern</th>
<th>Quote</th>
</tr>
</thead>
<tbody>
<tr>
<td>Decrease cost</td>
<td>“I can’t afford to go to the doctor. What am I supposed to do? I guess I just have to suffer. I think the next president should make all healthcare free.” (J.T.)</td>
</tr>
<tr>
<td>Decrease waiting time</td>
<td>“I tried to get an appointment. They told me I would have to wait. My tooth was really bad. I couldn’t wait for a month.” (E.B.)</td>
</tr>
<tr>
<td>Increase compassion</td>
<td>“He was bleeding from the cut. They told me to just sit down and wait our turn. Finally, a woman gave me a wet towel to try to clean the blood. But they should have helped us. The blood was awful.” (E.G.)</td>
</tr>
<tr>
<td>Increase hours of availability</td>
<td>“The clinic was closed when I came home from work. My daughter was sick, so we had to take her to the emergency room. If the clinic had been open, we would have gone there.” (S.D.)</td>
</tr>
</tbody>
</table>

One participant’s story was especially telling. With her daughter sitting on her lap, A.C. described the following experience:

I went there to have my baby. It was a very hard birth. I remember hurting so much. I asked the nurses to hold my hand. I asked again and again. I kept reaching out to them and they kept pulling away. They tied my hands down. Then the baby was born. Oh, but the placenta coming was very painful, too. They tried to make me take the baby to my breasts. I pushed the baby away. I don’t remember much after that except one old woman who wasn’t a nurse tried to help me. Later, when I was laying in my room, a social worker
came. He wanted to know if I really wanted my baby. The nurses told him I did not want my baby and that maybe I should give it away. All I wanted was to be out of pain, for someone to help me. I won’t ever go back there. I will stay at home.

Although this was the most touching story told about a lack of compassion, others told similar stories of perceived insensitivity, including being asked for the insurance card while they were throwing up.

Access emerged as a theme when participants discussed the use of the conventional healthcare system. Two issues of import were (a) length of waiting time for an appointment and (b) hours that clinics were providing services. One key informant, whose clinic was open outside of the usual business hours of from 9:00 a.m. to 5:00 p.m., stated that the clinic discouraged use of the facility for other than emergencies. Participants believed that they had to use the emergency room for primary care services because it was “always open.”

Although not a single question was asked about the cost or expense of symptom management, all participants talked about how their choices were influenced by cost. One participant (L.A.) stated that she took her current job for less pay because the health insurance was better. Another participant (J.T.J.) stated, “If we did not have insurance, I would work two or three jobs to pay for my kids’ care so they would not have to go without. Thank god, we both have good insurance.” Another participant (S.D.) talked about how she could not take her diabetes medication as prescribed because she could not afford it. (She reported paying more than $100 per month.) This same participant told a story of the cost of healthcare, which was sadly amusing.
My daughter was sick. She had fever and she kept vomiting. I tried to give her Tylenol and lots of liquids here at home. I took her to our clinic, and they said she was okay, but in the night she got worse. I took her to the emergency room. In there, they examined her and told me to take her home and give her Tylenol. She got better, but I got a bill from the hospital for $150. Imagine, $150 for Tylenol.

Although this participant told her story in an amusing way, the point of the story was not lost. She believed that if “all they were going to do is give her Tylenol, why did it cost so much?” Cost is a critical factor in seeking healthcare. Insurance and adequate resources facilitate access to healthcare, whereas lack of support and poverty serve as barriers.

A flowchart was developed based on these findings (see Figure 4). This chart is a depiction of my (etic) view of the symptom interpretation and management experience explicated in this study. The process that participants used to interpret and manage their symptoms was directed by a series of decisions beginning with whether or not they believed the symptom was a problem that warranted action. If the participant perceived the symptom to be problematic, the next decision was whether or not it was serious. For “not serious” symptoms, self-care was the first step in symptom management. If the symptom was perceived to be “serious,” the participants decided between the cost of seeking care and the likelihood of cure. If they were unsure of cure and cost was perceived to be high, self-care was the first step used in symptom management. If self-care failed to work, then conventional healthcare was used. If the participant perceived the symptom to be serious and the likelihood of cure to be high, they were initially
Figure 4. Symptom management flowchart.

Note. "Self-care" is any modality other than the conventional healthcare system. The "conventional healthcare" system infers use of a clinic or an emergency room.
more likely to seek care in the conventional healthcare system. The Common Sense Model overlies this process; that is, illness representation, coping, and appraisal are broader definitions of the detailed decision-making process described in the flowchart. The significance of the flowchart is discussed in Chapter 5.

**Summary**

This chapter presented the findings from the data (i.e., key informants, participant interviews, participant observations, literature, documents, artifacts, and photographs). The presentation of cultural, historical, and community background provided context for the symptom experience. These outer layers were peeled away to reveal the symptom interpretation and management experience of the participants: *el corazón de la cebolla*. The research questions provided structure within which the symptom experience was explicated. Exemplar cases of illness representation demonstrated complexity of the experience, which is depicted in a simplistic way by the Common Sense Model. The final issues (i.e., use of an emergency room, changes to the healthcare system, compassion, and cost) provide a contextual grounding, a layer of the onion, with regard to symptom interpretation and management. Each of these issues influences the decision-making process of the symptom experience.
CHAPTER 5

DISCUSSION

Introduction

In this urban mini-ethnographic study, symptom interpretation and management in a Mexicana/o community were examined. The Common Sense Model was used as a guiding framework (Leventhal et al., 1980). The suggestion by Diefenbach and Leventhal (1996) that cultural or socioeconomic factors may influence the illness representation was considered. The phenomenon was explicated using the explanatory model (Kleinman, 1980) in a semistructured interview format. This discussion is presented in a layered format, which is in keeping with the onion metaphor presented previously. The layers include (a) evaluation of the overall quality of the study; (b) quality of the study method; (c) study limitations; (d) summary of results; (e) reflexivity revisited; (f) implications for theory, research, and practice; and (g) conclusions.

Quality of the Study

The overall quality of this mini-ethnographic study was evaluated using Stewart’s (1998) criteria of veracity, objectivity, and perspicacity. The process for evaluating the quality of an ethnographic study compares to evaluation of other types of qualitative and quantitative criteria for reliability and validity.
The concept of veracity in ethnographic research is synonymous with validity. The implicit question is one of verisimilitude (truth) of depiction. Stewart (1998) contended that veracity of ethnographic research was present if there was (a) prolonged field work (at least 12 to 18 months), (b) a search for disconfirming observations, (c) good participative role relationships, (d) attentiveness to context, and (e) multiple modes of data collection. Although the study was not a maxi-ethnographic work, which would require a minimum of 1 year in the field, I spent 9 months in the field meeting with key informants, taking photographs, interviewing participants, and taking part in participant observations. Due to the exploratory nature of the study and difficulty recruiting participants, I did not make a concerted effort to search for disconfirming observations. Role relationships were not as in depth as one would expect when the researcher lives among the people being studied; however, key informants and participants as well as people encountered during participant observations were open and inviting to me. Attentiveness to context was the foremost reason this study was conducted in the field rather than in a clinical site, which is where much of the previous research has been conducted. I believed context was crucial to an understanding of the phenomenon of symptom interpretation and management.

Multiple modes of data collection were used in this study, including meetings with key informants; participant interviews; participant observations; immersion (to some degree) in culture-specific literature (e.g., fiction, film, and music); collection of artifacts; and photography. The major threats to veracity were
length of time in the field (I withdrew due to time constraints) and the need for further development of role relationships, which may have been enhanced by an insider-outsider team research approach.

Objectivity is the second criteria by which this study was evaluated for quality. Objectivity is synonymous with reliability, its implicit question being transcendence of perspectives. Stewart (1998) stated that objectivity is present if the following criteria are met: (a) trail of the ethnographer's path, (b) respondent validation, and (c) feedback from outsiders. Two other criteria are (a) interrater checks on indexing and coding and (b) maintenance of a comprehensive data archive. In terms of ethnographic research, Stewart contended that these last two criteria are of little use due to the context-specific nature of an ethnographic study.

During an ethnographic study, the researcher is learning. To provide a trail of the path taken requires a description of the method used for the study. A detailed "path" for this study was provided in Chapter 3. Audit trail, which is a commonly used term, implies the ability of future researchers to replicate the previous study. Due to the context-specific nature of the present study, replicability is not possible. However, an understanding of where I planned to go and how I planned to get there provides readers with the information necessary to evaluate the credibility of the research presented.

Respondent validation can be a dangerous task. The goal of this quality check is to give the participants an opportunity to validate their contributions to the research. However, the danger lies in the fact that, if the participants know that the
information being shared will have to be read by them at some point in time, it
may create an environment where they may share information they believe the
researcher wants to hear (to make it sound better) rather than to share the “true”
story of the phenomenon under study. Another problem with respondent validation
is the one I experienced. Six participants were asked to review the transcriptions of
their interviews. All of them stated, “It’s fine.” I believed this response was
somewhat erroneous, however. The participants may have been uncomfortable
reading about themselves or “criticizing” me. Participants during field work treated
me with great respect and some sense of awe. This phenomenon may have created
some bias on the part of the participants as well as during the respondent validation
process.

When I had the opportunity to present the work in progress at an academic
institution outside of Utah, feedback from outsiders was sought with regard to the
research during the field-work phase. However, feedback from this group of
outsiders was of limited benefit, as this institution’s research program was
quantitatively grounded. Therefore, the group lacked expertise in critiquing
qualitative work. During presentation of the research, outsider feedback will occur
in a number of forums, which may lead to additional analyses or alternate
interpretations. The use of interrater checks for indexing and coding as well as for
maintaining a comprehensive data archive might prove useful in validating the
research process. For an ethnographic study, these actions may not be especially
helpful. Due to the contextual nature of data collection, using interrater checks for
coding the data (interviews) removes the data from the very context in which collection occurred. If research teams versus a single investigator are conducting field work, this might be a useful evaluative process. The issue of a comprehensive data archive approaches the topic of replicability. The use of the data archive as an audit trail implies that another researcher could take the same journey as the researcher who collected the comprehensive data archive. Since the ethnographic study is a learning process for the researcher and many parts of this process are inherent to the researcher as an instrument in the study, there is naivété in this line of thinking. The “path” by which the data were collected was documented; however, even the detailed methods section falls short of identifying the intuitive, often serendipitous, nature of field work.

Perspicacity is the third criteria by which this study was evaluated. Perspicacity is synonymous with generalizability and external validity. The implicit question of perspicacity is whether or not there is applicability of insights elsewhere. Stewart (1998) maintained that perspicacity is present if the following occur: (a) intense consideration of the data and (b) exploration. Through these processes, Stewart contended that the ethnographic study can be evaluated for its applicability outside of the current study.

Intense consideration of the data requires what Stewart (1998) called “inspiration and perspiration” (p. 52). The researcher must spend considerable time immersed in the data coding and recoding. Each encounter with the data provides the researcher with a revisiting of the experience that may provide
insights. In terms of this data set, I revisited the interviews five separate times. It was not until the fifth interaction with the interview data that I had an insight as to what was present implicitly in the data. The final two interviews were used as a "check" for the emergence of new data. No new codes or patterns emerged from these interviews. Reading other ethnographic works (more perspiration), in combination with the multiple interactions with the interview data, created an environment where inspirations occurred—an identification of the process of decision making during an illness representation that was implicitly driven by cost considerations of healthcare modalities, especially the decision to use the conventional healthcare system.

The main threat to veracity, objectivity, and perspicacity was time. It is more difficult with focused ethnographic work to meet these criteria. This mini-ethnographic study met the basic criteria for veracity, objectivity, and perspicacity.

Quality of the Study Method

The method for this study was described in Chapter 3. In Chapter 4, the results of the study, using the ethnographic method, were described. This section evaluates the quality of the study.

The first formal step in quality assessment was using Kvale’s (1996) criteria for evaluation of the interviews themselves. Kvale described interviews as conversation. He stated, “Conversation is a basic mode of human interaction. . . . Through conversations we get to know people, get to learn about their experiences, feelings, and hopes and the world they live in” (p. 5). According
to Kvale, there are three types of conversations: (a) those that occur in everyday life, (b) those that occur in the literature, and (c) those that occur in the professions. The type of “conversation” focused on here is the professional “conversation” or interview. Kvale defined a professional conversation as “an interview whose purpose is to obtain descriptions of the lifeworld of the interviewee with respect to interpreting the meaning of the described phenomena” (pp. 5-6). The quality of the interviews was evaluated based on the criteria proposed by Kvale. These criteria are as follow:

- The extent of spontaneous, rich, specific, and relevant answers from the interviewee.
- The shorter the interviewer’s questions and the longer the subjects’ answers, the better.
- The degree to which the interviewer follows up and clarifies the meanings of the relevant aspects of the answers.
- The ideal interview is to a large extent interpreted throughout the interview.
- The interviewer attempts to verify his or her interpretations of the subject’s answers in the course of the interview.
- The interview is “self-communicating”—it is a story contained in itself that hardly requires much extra descriptions and explanations. (p. 145)

These criteria were used to analyze the pilot data as well as the data from the study interviews (see Appendix L). The criteria were met if each of these criteria was present at least 50% of the time. All of the interviews were evaluated, and it was found that the majority of the interviews met the criteria. However, there were three interviews that I found difficult to elicit responses other than “yes” or “no.” It is unclear why this difficulty occurred. This experience first happened in a Spanish-speaking interview and then occurred twice in English-only interviews,
which was somewhat confounding. However, these interviews provided insight into how the participants addressed symptom interpretation and management. The stories heard in the interviews were all similar.

Initially, it was intended that concurrent analysis would take place, allowing for the benefit of the previous interview when conducting each consecutive interview. However, interviews with participants came in bursts and did not allow for the transcription of previous interviews prior to conducting the next interview. I relied on field notes from each previous interview to guide the next encounter. Although not ideal, this technique was useful in preparing for the next interview.

In this study, language was a significant factor that influenced interview quality. Translation was accomplished with paid research assistants fluent in Spanish. However, neither research assistant came from the area where the Spanish-speaking participants originated. At first, this lack of commonality appeared to create somewhat of a dilemma, but as the process unfolded, I realized that gender and comfort level in conversing with people were more significant issues. Real-time translation occurred when I needed clarification; otherwise, the transcriptionist (who also served as the research assistant) provided translation with the transcripts.

Study Limitations

Every study has its limitations. Two major limitations were identified in this study of Mexicana/o symptom interpretation and management: (a) my lack of Spanish fluency and (b) my limited time in the field. A third limitation was
participant selection.

A part of the participant group spoke Spanish only. I was not fluent in Spanish. A bilingual research assistant was present during the Spanish-only interviews. Real-time translation occurred when I needed clarification of responses. However, my lack of fluency in the native language of the participants posed a risk; that is, cultural nuances inherent in the language in which the phenomenon originally was described may have been lost during translation.

The second limitation to this study was time spent in the field. Although I spent 9 months conducting field work, more time in the field would have allowed for site revisitation after analysis was in progress. The opportunity to return for second interviews with participants could have provided more in-depth discussion of illness representation and cost as an overarching factor in managing the symptom experience.

Sampling methods create bias as well. In this study, the limitation of participant self-selection creates a certain bias wherein the data lack a certain amount of generalizability.

Summary of Results

Contextualizing the symptom experience in an ethnographic study was imperative. During most of the data collection period, all participants had to leave the Poplar Grove area to seek conventional healthcare services, but the need to travel outside one’s own community is not unusual in the overall delivery of healthcare services. Towards the end of my time in the field, however, a clinic
offering flexible hours with bilingual providers opened within the boundaries of the study area. Had this clinic been in place at the beginning of the study or opened soon after I entered the field, participant responses might have been quite different. Through multiple data collection methods such as key informant meetings, participant observations, cultural immersion through literature (e.g., fiction, film, and music), document review, and photography, a portrait of the community was painted. Mexicana/o participants shared stories of symptom interpretation and management that were framed in the Latina/o community of Utah and grounded in their community of Poplar Grove. In the comfort of their own homes, participants selected symptom experiences to share. I used a Semistructured Interview Guide to explicate the emic perspective of the phenomenon.

The participants ranged in age from 22 to 63 years, were primarily women (89%), had a high school education or less (66%), and lived at 200% of the poverty level (72%) (Federal Guidelines, 2000). The majority of the participants was Catholic (67%), married (50%), and employed full time (50%) and were either uninsured or underinsured (66%). Two thirds of the participants were born in the United States and spoke English as their primary language. Although acculturation was measured, no relationships to other variables were examined. This participant profile is similar to that previously described in the literature (de Paula et al., 1996; Molina & Aguirre-Molina, 1994; Novello & Soto-Torres, 1993).
Other literature suggests that Latina/os do not seek care until quite ill and then they will use the emergency room for services, even for primary care (Council on Scientific Affairs, 1991). However, the current study group identified ethnocentric reasons for using the emergency department. When they used the emergency room for primary care services, it was because their primary care clinic was unable to accommodate them.

The University of Utah Research and Evaluation Program (1997) discussed the issue of a lack of respect as a barrier to care. The current study supported those findings. Participants identified a lack of “compassion” on the part of healthcare personnel as one reason they would hesitate to return to a particular healthcare establishment.

Two additional factors emerged from the interview experiences. First, when asked to describe a symptom, the participants needed prompting to “draw out” a detailed story of their symptom experience. However, when asked about an experience with the emergency room or how they would change the healthcare system, participants shared detailed stories of an illness or injury with little prompting. Their responses suggest that the illness did not occur until entry into the conventional healthcare system. Another possibility is that the illness episodes requiring interaction with the conventional healthcare system were severe enough that the participants had stored vivid memories of these experiences. An additional consideration is acute versus chronic symptoms experienced by the participants. Acute symptoms were more often just that, a symptom such as pain managed with
self-care modalities, whereas chronic symptoms were given “disease” labels, suggesting interaction with the conventional healthcare system. This difference suggests an illness representation for acute problems and a disease representation for chronic problems.

The second factor is the emergence of cost or expense of healthcare as an overarching issue regarding decisions about responses to an illness experience. Although I did not inquire specifically about cost as a barrier to receiving healthcare, 100% of the participants mentioned this issue in telling their stories. This issue was apparent in an ethnographic study conducted in the rural Mexican village of Pichataro (Young & Garro, 1981). Young and Garro first examined the illness representation of the villagers and then examined their decision-making process for addressing the illness or symptom. As previously stated, four factors influenced how illness episodes were managed: (a) gravity or seriousness of the illness; (b) availability of a home remedy; (c) belief that the home remedy would work; and (d) cost, access, and transportation. These issues were evident in the symptom experiences shared by the current study’s participants, validating that these factors were critical regardless of whether it is a rural Mexican village or a Mexican community in the United States. The process by which the participants managed their illness episodes is depicted in Figure 4. This flowchart was developed as a way to portray the process that emerged from this data set and its relationship to the Common Sense Model. The phases of the Common Sense Model (representation, coping, and appraisal) are present in broad terms in this
symptom management process, suggesting the applicability of the Common Sense Model in this study group.

My initial premise was that culture would emerge as a significant factor in symptom interpretation and management. However, poverty might be a broader issue implicit to the process. Young and Garro (1981) concluded:

To a considerable degree, in fact, the use of the traditional system of medical beliefs and practices may be seen as aspects of a community’s ongoing adaptation to its position of economic and social marginality in relation to the larger Mexican society. (p. 176)

This conclusion is applicable to the current study’s participants. The participants are poor and not a part of the dominant Anglo society in the community where they live; therefore, they may need to process healthcare decisions similar to the way the residents of Pichataro or any community of poverty might do.

Young and Garro (1981) further stated that a lack of the appropriate use of available healthcare services more likely is related to this social and economic marginalization. At the onset of the present study, I surmised that culture was a major factor in the use of healthcare resources. This assumption partially holds for the study group; that is, specific self-care modalities were culturally based. However, the broader issue appeared to be one of poverty that seemed to transcend culture. Cost considerations were at the forefront of each decision with regard to symptom interpretation and management for the participants in the study. The process does not appear to be culturally bound. Nevertheless, the process may be universal in its applicability, across disease processes, symptom experiences, culture, and poverty.
Reflexivity Revisited

As an instrument in this study, it was important to examine my feelings, expectations, and biases before entering the field. It is now equally important to reexamine those same areas of interaction and discuss how they were influenced by the study or the study was influenced by them. Through this process I can share what I learned from the participants and the process of conducting the research itself.

I began this study with a number of beliefs about people in general and more specifically the proposed participants. I believed that people are resourceful problem solvers who will act to solve problems (addressing the symptom experience) with the best of intentions regardless of outcome, using self-care as their first line of defense. The participants in this study were very resourceful. At times, they tried to treat a problem with self-care modalities that did not seem remotely physiologically related to the specific symptom. They were concerned about outcomes being positive rather than negative. Not one participant had given up on his or her symptomatology or that of a loved one, although many voiced frustration with the conventional healthcare system.

I believed that Mexicana/os have a well-developed arsenal of self-care modalities based on a culturally based belief system. At times, members of this group were creative in addressing their symptoms. However, less than one third of the participants described their use of culturally based beliefs such as a barrida in seeking resolution. I found the lack of culture-based management somewhat
surprising since one third \((n = 6)\) of the participants were recently relocated from Mexico, and others mentioned the use of alternative therapies by members of their families living outside of their homes. Those who talked about family members’ use of alternative therapies adamantly denied the use of anything they believed was unconventional. I was unsure whether this response was due to a sense of wanting to appear “mainstream” or simply a strong belief that alternative therapy was for “other” people. When I tried to probe this issue, the participants tended to become less engaged in the interaction.

I believed that a strong sense of family existed and that this must be acknowledged when interacting with this particular culture. This belief held true. All participants spoke convincingly of family ties, even negative ones.

When I started this process, I believed that culture influenced the depiction of an illness episode, but I found that the Mexicano culture was not the most powerful influence on the decision-making process used by the participants. The cost of healthcare services emerged throughout the study as the overarching theme affecting choice of method for symptom resolution. Although I knew from my own experiences that cost often affects the decision-making process, I expected culture to be more predominant.

Other experiences throughout the research process repeatedly reminded me that I was an outsider. I took a doctoral student colleague on a driving tour of the study area. Surprisingly, she stated, “Aren’t you afraid to be here around these people?” I spent many food breaks in a local taqueria (the best carne asada burrito
I had ever eaten), and I experienced a profound sense of differentness. I thought I was “mingling” with the locals. However, when they spoke to me in English rather than Spanish, I had this sense of feeling small. Did I make my patients feel “small” when attempting to address them in their native language? What is the right thing to do when caring for someone from a culture different from our own? Do we assume as the “all-knowing” Anglo that they prefer our butchered attempts at communication in their native language? I know that I will continue to make it a part of my practice to ask what language a patient prefers and to make every effort to ensure accurate communication when the language is other than my native language.

Overall, this process was one of learning. Many questions emerged from my experiences with the participants, the key informants, and the dissertation committee: (a) questions about the participants who participated and why, (b) questions about directing the inquiry using a model and whether that influenced the responses, (c) questions about agendas key informants may have had that could have created a bias even before I entered the field, and (d) questions about committee selection and integration that created an environment of support and learning. No matter the questions, there was still the journey. First and foremost, one must take the journey regardless of the challenges.

Implications for Theory, Research, and Practice

The implications of the study for theory, research, and practice are presented below and are examined individually.
Theory

The study used the Common Sense Model (Leventhal et al., 1980) as a guiding framework. As a guiding framework for development of the interview tool and for initial data analysis, the Common Sense Model was a useful theoretical base. Further development by Diefenbach and Leventhal (1996) included the addition of two influential factors: (a) culture and (b) socioeconomics. The current research suggests that cost (socioeconomics) may be a more influential factor than culture. The issue of poverty (cost consideration as a primary factor influencing decision making for healthcare) as an overarching theme may require more consideration in future development of the model.

Research

A basic premise for conducting research is to pose questions and to seek answers. However, a benefit of the research process is that often more questions are generated. Such questions provide fodder for future research projects. This study was no exception. Future research questions might include the following: (a) Is there a relationship between acculturation and the symptom experience? (b) Can this study be “replicated” with other marginalized groups? (c) Is culture or poverty more of an influencing factor in symptom interpretation and management? Many more questions could be formulated from the findings in the study relating to symptom management, decision-making processes, and application of other symptom models with similar study participants.
Practice

This research was undertaken in order to provide information that would be useful to clinicians, allowing them to increase their cultural competence with regard to Mexicana/o symptom interpretation and management. Information surrounding compassion and cost of healthcare was enlightening. Understanding how the participants processed their symptom experiences provided insights that clinicians can apply to practice. Understanding the complex decision-making process participants went through to address each symptom experience serves to enlighten clinicians who may be grounded solely in the conventional healthcare system. Rather than providing care from an ethnocentric, biomedical model, clinicians should be open to understanding the patients' pluralistic approach to healthcare issues. Programs of education and in-service at places of employment should address issues of cultural sensitivity or cultural competence. At the core of this patient approach to symptom interpretation and management is cost consideration. This consideration should be given much attention by clinicians in light of the current cost of healthcare and limitations of the U.S. healthcare system in providing cost-effective healthcare. I suggest that these study participants are not the only ones who incorporate cost consideration into their symptom interpretations and management experiences.

The dynamic nature of the symptom experience must be considered by clinicians as well. Clinicians who can anticipate and incorporate patient-based thinking into their considerations for patient care will create an environment in
which partnerships between patients and clinicians can occur. The ultimate goal is to provide an environment where the patient senses the clinicians’ responsiveness to, and acknowledgement of, cultural nuances. Both the patient and the clinician benefit from this partnership.

In a broader sense, these results provide insight for the development of healthcare services that incorporate the patients’ worldview into the delivery of services. Community partnerships have been developed that are successful in the provision of healthcare that is acceptable to those using the services. Governmental policy changes that require the development of community partnerships for the provision of healthcare services should be initiated.

Conclusions

This urban mini-ethnographic study explored symptom interpretation and management in a Mexicana/o community using the Common Sense Model as a guiding framework. The participant group ($n = 18$) was representative of samples described in previous research. The emic perspective of the symptom experience was explicated, lending support for the applicability of the Common Sense Model; however, the factors (culture and socioeconomics) that Diefenbach and Leventhal (1996) identified may be more influential than even they surmised. The implicit overarching theme that emerged from this data set was that of cost or the expense of healthcare. This factor, as it influences the symptom interpretation and management experience, demands further study. Cost also influences clinical practice. For example, the healthcare system in the United States is profit driven,
which may be a difficult concept to assimilate when one suffers from poverty. This study demonstrated that patients need choices based on their ability to afford medical services. Although the participants identified no deleterious outcomes, the potential for increased morbidity and mortality exists. How clinicians incorporate sensitivity with regard to culture and poverty into their clinical practices has potential to influence patient outcomes.
APPENDIX A

SEMISTRUCTURED INTERVIEW GUIDE
Symptom Interpretation and Management

1. What were the most common problems with your health or a member of your family that you experienced in the past month?

2. Please pick one of these for us to talk about in more detail.

3. What do you call this problem? What name does it have?

4. What do you think caused the problem?

5. What did this sickness do to you or your family member? How did it work?

6. How “bad” was it? (Makes assumption that this was a negative experience. If response is a positive one, will probe it.)

7. How long did it last? Was this a long or a short time?
8. What did you do for this problem? Why?

__________________________________________________________________________

__________________________________________________________________________

9. How well did it work?

__________________________________________________________________________

__________________________________________________________________________

10. Did you have to do anything else for this problem?

__________________________________________________________________________

__________________________________________________________________________

11. How did you feel (emotionally) when you experienced this problem?

__________________________________________________________________________

__________________________________________________________________________

12. If (emotionally), did that change how you took care of the problem?

__________________________________________________________________________

__________________________________________________________________________

13. Who helped you with this problem in your home or community?

__________________________________________________________________________

__________________________________________________________________________

14. Would you show me what you have in your home to take care of problems like the ones you have mentioned? (Add probes such as medicine cabinet, cupboard with medicines, shrine, first aid kit, etc.)

__________________________________________________________________________

__________________________________________________________________________

__________________________________________________________________________
APPENDIX B

MODIFIED INTERVIEW GUIDE
Introduce myself: Doctoral student at the University of Utah College of Nursing interested in how persons of Mexican descent think about and manage common health problems in their homes.

Purpose: To find out more about what are the most common health problems you are experiencing, what they meant to you, and how you handled them. By sharing this information, you will be helping your people by educating people like me so that we can better work together to provide services that you want and need.

First go over the consent.

Talk about no connection with the Immigration and Naturalization Service or other reporting agency.

Answer any questions at this point.

Do demographic questions. . . . Return at end if any problems getting it completed.

Reassure them about how taping the interview will work. Each person will introduce themselves on tape. At another time they will have the opportunity to make sure the taping was accurate.

**Question 1:**
What are the most common health problems you or your family members have experienced in the past month or so?

________________________________________________________________________

________________________________________________________________________

________________________________________________________________________

**Question 2:**
Would you pick one of these health problems and tell me about it?

________________________________________________________________________

________________________________________________________________________

________________________________________________________________________

(Probe): How did it start?

________________________________________________________________________

________________________________________________________________________

What did you call it?

________________________________________________________________________
What did you think was causing the problem?

How long did you think it would last?

How long did it last?

What did you do to try to make the problem better?

Did it work?

Did you need anyone to help you with this problem?

If yes, who was it?

What did they do?

Did it work?

If you did nothing, did you think anything bad would happen because you did not do anything?
Question 3:
Are there any other times you can remember dealing with a health problem that either you or your family member had that you would like to share?

If yes, follow format for Question 2.
(Probe) How did it start?

What did you call it?

What did you think was causing the problem?

How long did you think it would last?

How long did it last?

What did you do to try to make the problem better?

Did it work?

Did you need anyone to help you with this problem?

If yes, who was it?
What did they do?

Did it work?

If you did nothing, did you think anything bad would happen because you did not do anything?

**Question 4:**
What do you keep in your home to help you take care of health problems that you or your family experience?

May I see these things?

**Question 5:**
Is there a time when you had to go to an emergency room because of a health problem that one of you experienced?

If yes, can you tell me about that experience?

If no, what do you think the emergency room is for?

What types of problems?
Question 6:
Do you have a regular place you can go to for health problems?

If yes, name of place and location.

If no, why not ($$$, insurance, ???)?

Not feel it is needed because:

(Probe): Did they have regular healthcare such as checkups, immunizations, pap smears, etc. where they lived before?

Question 7:
Have you ever had the opportunity to use the services of a healer?

If yes,

What were they called?

What was the health problem you had?

What did they do for you?
Did it work?

Why did you choose to go to the ____?

If no, Do they know anyone who did?

What did they think of that person going to see a ____?

Question 8:

Have you ever felt that you could not get healthcare here because of your ethnicity?

If yes, what happened?

If no, did you experience any other barriers (problems)?

Question 9:

If you have ever had problems with getting the care you thought you needed while living here, what could the system do to make it better for you?
Question 10:
Is there anything else you want to share with me at this time about what we have talked about?

Closure:
Thank them for the interview. Ask if I can come back with the transcripts for them to review for accuracy. Let them know they can page me if they have anything they want to add.

THANK YOU! MUCHAS GRACIAS!
APPENDIX C

CULTURAL IMMERSION
Books


**Film**


**Music**


[Songs on the juke box at Mariscos, 400 South 900 West, Salt Lake City, UT]
APPENDIX D

DEMOGRAPHIC INFORMATION TOOL
ID#: __________

Interview date: __________

Location: __________

Age: __________ years

Gender: M (1) F (2)

Marital status: _ (1) Single
 _ (2) Married
 _ (3) Living with partner
 _ (4) Separated
 _ (5) Divorced
 _ (6) Widowed

Religion: _ (1) Catholic
 _ (2) LDS [Church of Jesus Christ of Latter-day Saints]
 _ (3) Other: ____________________________

Education (highest level completed):
 _ (1) 0 to 8 years
 _ (2) 1 to 3 years of high school
 _ (3) High school graduate or GED [general educational development certificate]
 _ (4) Some college or technical school
 _ (5) Associate's degree
 _ (6) Bachelor's degree
 _ (7) Postgraduate education

Where born: __________________________

How long in the United States? ____ years

How long in Salt Lake City: ____ years

How long in Poplar Grove: ____ years
Language use scale: 1 = Spanish only  
2 = Mostly Spanish  
3 = Spanish and English equally  
4 = Mostly English  
5 = English only  

Language in home: 1 2 3 4 5  

Language read/speak: 1 2 3 4 5  

Language with friends: 1 2 3 4 5  

Language think in: 1 2 3 4 5  

Family structure:  

Clinic or primary care provider?  
Who or where?  

When was last visit?  
Why?  

Who works outside the home?  

What type of work do they do?  

Is this work:  
(1) Full time  
(2) Part time (< 40 hours/week)  

Insurance:  
(0) No  
(1) Yes  
Type:  

Income:  
(1) Less than $5,000  
(2) Between $5,000 and $9,999  
(3) Between $10,000 and $14,999
<table>
<thead>
<tr>
<th></th>
<th>(4) Between $15,000 and $19,999</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>(5) Between $20,000 and $29,999</td>
</tr>
<tr>
<td>---</td>
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<tr>
<td></td>
<td>(6) Between $30,000 and $39,999</td>
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<td>--------------------------------</td>
</tr>
<tr>
<td></td>
<td>(7) Between $40,000 and $49,999</td>
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<td></td>
<td>(8) More than $50,000</td>
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APPENDIX E

RECRUITMENT FLYER IN ENGLISH
Help! Help! Help!

*A Study About Your Health*

Persons of

>Mexican Heritage

>18 years or older

>Live in Poplar Grove (bordered on south by railroad tracks)

Takes 30-60 minutes
Interview only-----NO test taking

*English or Spanish*

You will be paid $20 for the interview

If interested please call Melody at 965-3900
APPENDIX F

RECRUITMENT FLYER IN SPANISH
Ayuda! Ayuda! Ayuda!

*Un Estudio Acerca de su Salud*

Personas de

>herencia Mexicano

>Mayores de 18 años

>Que vivan en el area de Poplar Grove (bordered on south by railroad tracks)

Se tomará de 30-60 minutos
Entrevista solamente----no se le hará ningún examen

Ingles o Español!

Si le interesa ser entrevistado usted recibire $20 por su tiempo

Favor de llamar Melodia al 965-3900
APPENDIX G

CONSENT TO BE INTERVIEWED IN ENGLISH
CONSENT TO BE INTERVIEWED

A Study of Symptom Interpretation and Management
in a Mexican American Community
Melody A. French, RN, Ph.D.(c)

You are invited to participate in a study of health and illness experiences in your community. The study is being conducted by Melody French who is a nurse and a doctoral student at the University of Utah. This study will consist of interviews asking about experiences called symptoms. The interview will look at those symptoms that are experienced by yourself or someone in your home or family that you are familiar with. The information that you share will be used to learn more about the health care needs of Mexican American persons here in Salt Lake County.

Your help with this study is voluntary. You may choose not to be interviewed or may stop the interview at any time. As far as the researcher can tell there is no risk to you for being interviewed. As a member of a Mexican American community your participation in this interview may help others who are in your community or workers in the health care field.

The time it will take to talk with you is about one hour, however the interview can take as long as you need to share your information. This information is your story of these symptoms. Although the interviewer will ask questions to guide the conversation, your story is the focus of the time. The interview will be recorded using a tape recorder. The interviewer may take notes during the interview. The tapes will be kept in a locked cabinet by the researcher. There may be times when a research assistant will be present during the interview. The research assistant will be present mostly to help with language translation if needed.

There may be items, such as herbs, photos, and recipes, which you choose to share with the researcher which help you tell your story about your symptom experience. These will be used to make your story stronger and will not be connected to you personally in any way.

All of the information you share with the interviewer will be kept confidential. Even though it is very important to keep your information confidential, sometimes this is not possible. Your name will not be used at any time when this information is shared with professors or when this information is printed in a magazine, book or newspaper.

If you have any questions please call me, Melody French at 241-5139 or leave a message with the person who told you about this study. You may also call my professor, Susan Beek at 585-9609, if you have any questions about this study in your community.

If you are willing to share your story with me sign your name below. You will receive a copy of this form.

I voluntarily agree to be interviewed.

________________________  ________________________  ________________________  ________________________
Your Name               Date                     Melody French                  Date
APPENDIX H

CONSENT TO BE INTERVIEWED IN SPANISH
Consentimiento para ser Entrevistado

Para un estudio de interpretación de síntomas y manejo en la comunidad Hispano Americana introducida por Melody French enfermera registrada familiar.

Usted está invitado a participar en un estudio de salud y enfermedades de su comunidad. Este estudio será conducido por Melody French quien es enfermera y estudiante Doctorada en la universidad de Utah. Este estudio consistirá de entrevistas y preguntas acerca de experiencias llamadas síntomas. La entrevista se tomará de los síntomas que usted ha tenido o de alguien de su familia en su casa o algún familiar que usted conozca. La información que usted nos de, servirá para aprender más acerca de la necesidad de la salud de personas Hispano Americanas aquí en Salt Lake City, Utah.

Su ayuda para este estudio es voluntaria. Usted puede decir que no desea ser entrevistado, usted no tiene ningún riesgo por ser entrevistado. Como miembro de la comunidad Hispano Americana su participación en esta entrevista puede ayudar a otras personas en su comunidad o a trabajadoras del centro de salud.

El tiempo que se tomará para hablar con usted es aproximadamente una hora. La entrevista puede tomar el tiempo que usted necesite para darnos su información. Esta información es su historia de estos síntomas, aunque el entrevistador le hará preguntas para guiar la conversación lo más importante es lo que usted nos diga. Nosotros grabaremos la entrevista, quien lo entrevistará también tomará notas por escrito. La información grabada será guardada bajo llave por el investigador. Habrá veces cuando algún asistente estará presente durante la entrevista. Dicho asistente estará ahí principalmente para ayudar a traducir si fuera necesario.

Si usted tiene algo tal como yerbas medicinales, fotografías o recetas, que usted quisiera compartir en la entrevista las cuales nos ayudarían a entender mejor su caso si gusta usted puede traerlas.

Todo su información será confidencial. Aunque es muy importante mantener su información confidencial, algunas veces esto no es posible. En dado caso su nombre no será usado cuando esta información sea compartida con profesores, revistas, libros o periódicos.

Si usted tiene algunas preguntas favor de llamar a Melody French al 241-5139 o deje mensaje con la persona que le dijo acerca de estos estudios, usted también puede llamar a mi profesora Susan Beck al 585-9609.

Si usted está de acuerdo a compartir su historia conmigo por favor firme su nombre en el lugar indicado. Usted recibirá una copia de este formulario.

Voluntariamente acepto ser entrevistado (o).

______________________________     ________________________________
Name                          Melody French

______________________________     ________________________________
Date                          Date
APPENDIX I

CONSENT TO BE PHOTOGRAPHED IN ENGLISH
CONSENT TO PHOTOGRAPH

A Study of Symptom Interpretation and Management in a Mexican American Community
Melody A. French, RN, PhD(c)

For the purpose of this study you are being asked for permission to take your photograph. Your participation is voluntary. By saying "no" this does not mean that the story you have shared is not important or will not be used. The picture will be used to make the story stronger.

Your name will not be used unless you say it is okay.

I give my voluntary consent for Melody French to take my photograph and use it in presenting the results of her research.

_________________________  _______________________
   Name                    Date

I give my permission for Melody French to use my name when showing this photograph.

_________________________  _______________________
   Name                    Date
APPENDIX J

CONSENT TO BE PHOTOGRAPHED IN SPANISH
Consentimiento para tomar Fotografías

Para un estudio de interpretación de síntomas y manejo en la comunidad Hispano Americana introducida por Melody French.

Para el propósito de este estudio se le pedirá su permiso para ser fotografiado. Su participación es voluntaria. El decirnos que “no”, no quiere decir que la historia que usted ha compartido con nosotros no es importante o que no vaya ser usada. Su foto se usará para hacer su historia más creíble.

Su nombre no se usará, solamente que usted lo acepte.

Yo doy mi consentimiento voluntariamente a Melody French para que tome mi fotografía y la use para la presentación de este estudio.

___________________________  ______________________
Nombre                     Fecha

Yo le doy permiso a Melody French de usar mi nombre al enseñar esta fotografía.

___________________________  ______________________
Nombre                     Fecha
APPENDIX K

INTERVIEW GUIDE FOR KEY INFORMANT INTERVIEWS: PRINCIPALS
Principal:

How long with the school?

Do you live in this community?

How many students in the student body?

What are the boundaries for Franklin’s catchment area?

What other schools are within these same boundaries?

How many students speak Spanish only?

How many students speak English only?

How many students are bilingual (Spanish/English)?

How many of your teachers are bilingual (Spanish/English)?

What role does the school play in the community?

You mentioned a community meeting. What is the purpose of these meetings?

How often do you have these meetings?
Who leads the community meetings?

Who sets the agenda for these meetings?

What percentage of your student body is current on immunizations at the time of registration?

What health issues do your students deal with?

Is there a high absenteeism rate due to illness?

Do you know how these health issues are handled?

What healthcare services are readily available to your students and their families?
  _ within walking distance
  _ by private car
  _ by public transportation

What are the main concerns for these children?
  _ from your perspective
  _ from their parents' perspectives
  _ from the community's perspective

Are there things that you are aware of that have been done to address the healthcare needs of the community?

What?

_ Successful
_ Not successful

Are there any other sources of community information you can share that might assist me in building a portrait of the Poplar Grove community?
APPENDIX L

KVALE CRITERIA CHECKLIST
1. Extent of spontaneous, rich, specific, and relevant answers from the interviewee

1  2  3  4  5  6  7  8  9  10

2. Shorter interviewer questions . . . longer subject answers

1  2  3  4  5  6  7  8  9  10

3. Interviewer follows up and clarifies meanings of relevant aspects of the answers

1  2  3  4  5  6  7  8  9  10

4. The interview is interpreted throughout the interview

1  2  3  4  5  6  7  8  9  10

5. Interviewer attempts to verify his or her interpretations of answers in the course of the interview

1  2  3  4  5  6  7  8  9  10

6. The interview is a “self-communicating” story contained in itself that requires very little description or explanation

1  2  3  4  5  6  7  8  9  10
REFERENCES


Koss, J. D. (1980). The therapist-spiritist training project in Puerto Rico: An experiment to relate the traditional healing system to the public health system. *Social Science and Medicine, 14B*, 255-266.


