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Exploring the Expression of Pain by Limited English Proficient Latino Immigrants  
in Language and Culturally Discordant Health Encounters

by

Jacqueline L. Gregory

DISSERTATION

Submitted in partial satisfaction of the requirements for the degree of

DOCTOR OF PHILOSOPHY of NURSING

in

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By

Jacqueline L. Gregory

## Dedication and Acknowledgments

With ease and the utmost respect I dedicate this Dissertation to Dr. Kit Chesla, I am a better person because of you. From the deepest part of my soul I am in gratitude for the indispensable educational experience you chose to provide me. With you by my side, I persevered through relentless trials and tribulations and for that I remain, in the deepest gratitude. To the Creator and Grandfather of all things thank you for giving me a purposeful life and guiding this study. To the courageous and loving Latino participants who opened their homes and hearts to share their stories and make this dissertation possible, Gracias. To Romy, your prayers and humbly pleading on my behalf that the people welcome me into their life made this project possible you're unforgettable. My sincere gratitude To Dr. Roberta Rehm for her unwavering dedication to this project from start to finish you guiding me with such grace and expertise, Gracias. A special thank you to Dr. Pinderhughes for agreeing to be a part of my educational experience while appreciating where I came from, and where I needed to go, Gracias. To Dr. Kathy Lee for years of encouragement and for providing the Symptom Management T32 funding a vital component to my receipt of a PhD, I am forever grateful. To my loving Brother Dr. Eric Lopez for his unconditional love and support are journey has just begun. To my dearest friend and Editor Bruce Smith for your dedication to this project and the Latino people countless, days and night my gratitude cannot be expressed in words except I love you brother. To Dr. Shirley Manly-Lampkin my deepest respect for your open door policy while at UCSF and for your continuous dedication and support especially to students of color your, I will pass it on. To all the UCSF professors who found it in their hearts to honor my learning differences along the way, thank you. To Kirk Hudson in the IT department of UCSF thank you

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## Abstract

### Exploring the Expression of Pain by Limited English Proficient Latino Immigrants in Language and Culturally Discordant Health Encounters

The purpose of this interpretive study was to explore the expression of GI pain by non-English-speaking (NES)/ limited-English-proficient (LEP) Latino immigrants in language and cultural discordant health encounters. Language discordance prevents NES/LEP Latinos from reporting symptoms of abdominal pain to a provider. Furthermore, the extent of this communicative inability was correlated with negative health care outcomes such as longer wait times before receiving primary clinical assessment for acute GI symptoms in the emergency room.

**Method.** Interpretive phenomenology guided the design and analysis. Two in-depth individual interviews were conducted with a purposive sample of 13 adult Latino participants who had LEP, a history of GI pain, and treatment in U.S. health care. Participants were undocumented, Central Valley residents who were reluctant to participate in research due to fears of deportation. Interviews focused on the history of present illness, beliefs about their illness and treatments needed, and direct narratives regarding receipt of health care in the U.S. for their GI pain.

**Results.** Participants' perceived barriers to communicating GI illness concerns included undocumentedness, fear of deportation, personal healthcare beliefs and practices, lack of insurance, low health care literacy, and limited income. Participants reported receiving ineffective/fractured care, and feeling uncared for by doctors. Discriminatory practices, largely because of their ethnicity, LEP and low income were commonplace. Aids to communicating GI illness concerns included trust, time, attention, respect, consistent follow up care, and doctors

who showed concern. Latino coping processes included following western medicine advice and prescriptions, as well as reliance on folk medicine, God, and family. Despite these coping strategies, participants experienced considerable untreated pain, delayed or ineffective diagnostic work-ups and limitations on diagnostic tests (i.e., EGD) because of their LEP, insurance status and/or immigration status.

**Conclusion:** Structural and interpersonal barriers were identified by Latino immigrants regarding communicating GI illness concerns in situations of language and cultural discordance. Improvements at both the interpersonal and institutional levels are required to begin to address the disparities in health care expressed by this population.

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## **Language Discordance and Latino Gastrointestinal Health**

Abundant research shows that *language discordance*—defined as differences of language between patients and their health care providers—often results in disparities of health care delivery and health status (Flores, Abreu, Olivar, & Kastner, 1998; Pérez-Stable, Nápoles-Springer & Miramontes, 1997). Among the important areas of clinical interest for caregivers, researchers, and policy makers are the effects of language discordance on health care disparities experienced by Latinos with gastrointestinal (GI) illness. Research suggests that GI disease is one of the most common health conditions occurring in the United States; however, to date little research has explored the expression of GI pain by non-English-speaking (NES)/ limited-English-proficient (LEP) Latino immigrants in language- and culture-discordant clinical encounters. For Latino immigrants, the ability to communicate and describe symptoms of illness is essential for safe and correct assessment, diagnosis, and treatment (Diaz et al., 2009; Flores, 2006).

In this introductory chapter I will first give a brief overview of the literature that sets up the significance of the project proposed. A more detailed review of this literature is provided in Chapter 2. Second I will briefly review two theories that sensitize the interpretive phenomenological research that I conducted: acculturation theory and the symptom management model. Third I will describe the specific aims to the study.

In subsequent chapters I will present a thorough review of the literature on quality of healthcare and health outcomes in language discordant health care encounters between Latinos and US healthcare providers. Chapter 3 describes the methods employed in completing this dissertation project. In Chapter 4, I present the central findings of this research project.

Employing an interpretive phenomenological approach, I investigated the health experiences of Latino patients with LEP who are experiencing chronic abdominal pain. Their narratives and reflexive comments are summarized and interpreted. Chapter 5 presents the discussion of the findings and implications for education research and practice.

### **BACKGROUND AND SIGNIFICANCE**

As of 2010, the Latino population in the United States was estimated to be 50.5 million (U.S. Bureau of Census [BOC], 2010). Latinos are the fastest growing ethnic group in the nation and are projected to constitute 30% of the U.S. population (132.8 million) by the year 2050. Culture and language significantly influence how America's over 35.5 million Spanish-speaking Latinos communicate their illness symptoms (BOC, 2009).

Studies show that health care systems are inundated by patients who present with various GI conditions. In 2006, for example, 35.9 million people suffering from GI conditions sought care from providers (CDC–National Center for Health Statistics [NCHS], 2008). The prevalence of GI illness among Latino immigrants is not well documented. However, one study found a recent rise in the prevalence of GI illness among Latinos (i.e., gastroesophageal reflux disease [GERD], Yuen et al., 2010) and inflammatory bowel disease (Hou, El-Serag, & Thirumurthi, 2009). Although there is limited research on health care disparities related to GI illness, studies suggest that Latinos frequently present with more advanced stages of GI illness (e.g., hepatitis related cirrhosis) and experience higher morbidity than do non-Latino Whites (Blessman, 2007). Researchers have not closely examined the causes of Latinos' more advanced GI illnesses and worse health outcomes. Some have hypothesized that language and culture play a role in the access and acceptability of health care for Latinos. For example, cultural beliefs about the

causes and treatments of illness may create barriers in health-seeking behaviors, and these barriers may lead to delayed care and treatment of Latino patients (Calvillo & Flaskerud, 1991). Despite the high prevalence of GI conditions, few studies have examined how Latinos' culturally and linguistically unique ways of reporting symptoms may affect the diagnosis and treatment of illness and health care outcomes in this population (Barakzai et al., 2007; Diaz, 2009; Minsky, Vega, Miskimen, Gara, & Escobar, 2003; Wu, Banks, & Conwell, 2009). However, one study reported that language discordance prevented NES/LEP Latinos from reporting symptoms of abdominal pain to a provider. Furthermore, the extent of this communicative inability was correlated with negative health care outcomes such as longer wait times before receiving primary clinical assessment for acute GI symptoms in the emergency room (Wu et al., 2009). Moreover, this research suggests that this population expresses GI symptoms in culturally specific ways (e.g., cold bones; Barakzai et al., 2007). This communicative cultural specificity places Latinos at risk for misdiagnosis of illness symptoms and poor medical health care outcomes (Wu et al., 2009)

A few cross-cultural examinations of specific chronic conditions suggest that Mexican Americans do report symptoms in unique ways. Barakzai and colleagues (2007) conducted a retrospective review of charts of Mexican-American patients diagnosed with irritable bowel syndrome (IBS). The researchers found that Mexican-American patients reported symptoms unrelated to the GI system, such as dizziness (11%), myalgias (11%), and headache (14%), symptoms that were different in nature, pattern or degree from non-Mexican-American patients' reporting IBS. Additional findings included patients' descriptions of symptoms that used culturally specific symptom expressions; in some instances, these expressions were metaphoric



or idiomatic such as “cold bones” and “cold stomach” (Barakzai et al., 2007, p. 263). Similarly, Meshack and colleagues (1998) conducted the first comparative study to examine differences between Mexican Americans and non-Latino Whites in their reporting of symptoms of myocardial infarction (MI). The authors also discovered that Mexican Americans were more likely to report symptoms of MI in terms of having “upper back pain” and “palpitations,” whereas non-Latino Whites were more likely to report symptoms of MI in terms of having “chest pressure” and “jaw pain.”

The missed diagnosis of abdominal pain can have negative outcomes beyond the progression of disease. In a survey conducted by Magni (1998), Latinos who reported symptoms of chronic abdominal pain were found to have higher rates of suicidal ideation and suicide attempts (up to three times more frequently) than were Latinos without chronic abdominal pain. Given the health care disparities experienced by Latinos, additional knowledge regarding how Latinos present and report GI symptoms is vital for improving assessment, diagnosis, and treatment for this ethnicity (Diaz, 2009; Minsky, 2003; Rueda-Lara, 2003). Recent research has not identified solutions for resolving or mitigating the challenges imposed by language discordance as experienced by NES/LEP Latinos (Flores, 2005; 2003). Accordingly, more investigation into how Latinos present and report GI symptoms in contexts of both language discordant patient and non- language discordant –provider communication is needed.

## **THEORETICAL UNDERPINNINGS**

### **Berry’s Acculturation Model**

Berry’s model of acculturation illustrates the processes by which cultural groups make contact, interact with and then adapt in a plural society. Berry’s is a two-dimensional model

based on the principles of cultural maintenance and contact-participation (Berry, 1980). In Berry's view, *cultural maintenance* refers to the extent to which individual's value and desire to maintain their cultural identity. *Contact-participation* refers to the extent to which persons value and seek out contact with those external to their own group and the point to which individuals wish to take part in the daily life of the larger society (Berry, Kim, Minde, & Mok, 1987; Berry, 2003).

Berry's model features four distinct acculturation strategies: *integration*, *assimilation*, *separation*, and *marginalization* (Berry, 1980). Berry assumes that acculturation is not linear; but rather is a two-dimensional process that induces reciprocal changes in the interacting cultures. Acculturation processes do not require an individual or group to give up their culture to adapt to new society and instead has two dominant aspects: preservation of one's cultural heritage and adaptation to the host society (Berry, 1980).

Berry (1980) defines *acculturation strategies* as the "modes by which immigrants interact with the host society" (Berry, 1980. p. 13). Although Berry assumes that immigrants generally choose how they want to acculturate he acknowledges that often groups find themselves forced to follow a specific strategy ( e.g. marginalization) by the dominant society (Berry, 1997). Berry's model proposes four acculturation strategies: *assimilation*, *integration*, *separation*, and *marginalization* (Berry, 1980). These strategies are discussed as follows:

*The integration strategy* refers to an attempt on the part of an immigrant to adhere to the norms of their cultural heritage while seeking to participate in the larger society (Berry, 1980, p.13). Integration is a strategy that is directed toward building relationships with the dominant group (Berry, 1980, 1988). According to Berry (1980) integration can unfold where reciprocal

accommodation exists; here *reciprocal accommodation* refers to acceptance by both groups to live as culturally different people (Berry, 1980, 1991). Berry suggests that immigrants who chose integration as an acculturation strategy experience more acceptance. For example, immigrants become accepted by the dominant society while retaining a great deal of their original culture (Moghaddam, Taylor, & Lalonde, 1987; Berry, 1980).

*The assimilation strategy* of acculturation is characterized by a lack of engagement in one's culture of origin alongside an attempt to become a part of the dominant group (Berry, 1980, p. 13; Berry & Sam, 1997). Initially immigrants who chose an assimilation strategy reject their original culture and in turn may transition with minimal difficulties with socio-cultural adaptation (Berry, 1980, p.13).

*A separation strategy* entails an ethnic group's adhering exclusively to its culture of origin" (Berry, 2002). Immigrants who use separation strategy maintain their engagement in their culture of origin and maintain relationships with fellow nationals while rejecting the host culture and relationships with host nationals (Kosic, 2002).

*A marginalization strategy* entails individuals' or groups' who lose contact with both their group and the dominant group (Berry, 1980, p. 15). Berry asserts that marginalized populations suffer high level of anxiety, a loss of identity and, finally, feeling of isolation (Berry, 1980; 1989). Moreover, Berry suggest, that it is not likely a group would voluntarily choose this acculturation strategy. Finally, in the process of adaptation, immigrants proceed through multiple phases of acculturation; this transformative process can result in conflict creating stressors—referred to in the literature as *acculturative stress* (Berry, 1980, 1988).

*Acculturative stress* refers to stress “in which the stressors are identified as having their source in the process of acculturation” (Berry & Sam, 1997; Berry 1980, p. 21), asserts, that a set of stress-related problems occur during acculturation; these include (a) lowered mental health status (e.g., confusion), (b) feelings of marginality and alienation, (c) heightened psychosomatic symptom level, and (d) identity confusion (Berry, 1980; Berry, et al., 1989). According to Berry et al., among the four acculturation strategies, separation and marginalization are associated with the highest levels of acculturative stress (Berry, 1989). Berry further asserts that acculturative stress can lead to heightened levels of depression (linked to the experience of cultural loss) and anxiety (linked to lack of knowledge on how to live in a new society) (Berry & Ataca, 2000; Berry, Kim, Minde, & Mok, 1987).

### **Symptom Management Model**

Few studies have used a theoretical framework when examining modes of symptom expression used by diverse Latino populations (Jacobs et al., 2008). Theoretical frameworks increase clarity regarding the potential impact of key factors (e.g., acculturation, language proficiency) on how a Latino population reports GI symptoms (Mejia, Kaufman, Corbie-Smith, Rozier, Caplan, & Suchindran, 2008). A theoretical framework can also inform clinical understanding of how key factors influence how symptoms are experienced and reported among Latino sub-populations (Mejia et al., 2008).

The symptom management theory (SMT) will be used to investigate symptom expression among Latinos—in order to identify cultural similarities and differences that characterize minority subpopulations and the predominant cultural groups (Jacobs et al., 2008). The SMT

will be used as a sensitizing conceptual framework to examine the expression of pain by NES/LEP Latino immigrants in language and cultural discordant health encounters.

SMT has several established key domains—*symptom experience*, *symptom management strategies*, and *symptom outcome*—and numerous factors and variables within the model (Dodd, 2001, p. 670). Each is briefly reviewed here.

According to Dodd et al., (2001), *symptom* refers to “a subjective experience that is reflected by a change in the “biophysical functioning, sensations, or cognition of an individual” (p. 669). *Symptom experience* refers to a change in an individual’s body that compels the person to search for the cause of the change and to ask herself or himself how the change impacts her or his health status (Dodd et al., 2001). Three factors continuously interact with symptom experience:

- *symptom perception*—when one feels a change—a departure from the normal function of the one’s body;
- *symptom evaluation*—the way in which one characterizes one’s symptom experience; this characterization may be in terms of symptom cause and treatment options and necessity; and
- *symptom response*—the way in which one reacts to a symptom; for example, emotional illness behavior as influenced by culture (e.g., fatalism; Dodd et al., 2001; Humphreys et al., 2008; Comas –Diaz, 2006 ).

**Symptom management strategies.** *Symptom management strategies* refer to interventions implemented by the provider or patient in attempts to abate or lessen any negative experience that a symptom may cause by way of “biomedical, professional and self care strategies” (Dodd et al., 2001, p. 673). Symptom management strategies include directive

questions designed to reveal important background information that informs intervention strategies (Dodd et al., 2001; Humphreys et al., 2008; Linder, 2001). For example; a) what strategies are being implemented?, b) *when* and *where* will the strategies be implemented?, c) what is the *rational* for implementing the strategy?, d) what is the *quantity* (i.e., dose) of the intervention and, *who* will implement the intervention?, finally, e) *how* will the intervention be “*delivered*” (Dodd, 2001, p. 673). SMT recognizes that the various management strategies can be implemented with individuals, family, or community; an example of a symptom management strategy is “self-care” (Dodd et al., 2001; Humphreys et al., 2008, p.; Jacobs et al., 2008). In the view of SMT, *self-care* refers to the care provided by individuals who become active in their personal symptom management in attempts to limit the potential negative effects of their illness experience and restoring their health and wellbeing (Campbell, 2008; Humphreys, 2008). Finally, the processes of symptom management are positioned within the *dimensions of nursing science* located in the SMT (Humphreys, 2008; Linder, 2010). These domains include *person, health and illness*, and the *environment* (pp.670-671). Moreover, all three domains have distinct, interrelated sub-variables; these sub-variables are discussed.

According to Humphreys (2008), symptoms are influence by the *person domain*, which comprises demographic and sociological variables. It is important to note here that the person domain can be developed to be applied to diverse groups having various symptoms; Dodd, 2001). Moreover, the health–illness domain consists of the evaluation of risk factor, health status and disease. For example, an important risk factor includes the impact of culture and language on the way patients’ experiences and report symptoms (Dodd, 2001; Humphreys, 2008; Janson, Carrieri; 1986). Finally, the *environment domain* also located within the dimensions of

nursing science refers to the “conditions” where the symptom was examined (Dodd, 2001, p. 670; Humphreys, 2008, p. 146). For example, the environmental domain encompasses *physical, social, and cultural* sub-domains (Dodd, 2001). Furthermore, within the cultural sub-domain lie the beliefs, values, and practices that are “unique to a person’s identified ethnic, racial, or religious group” these factors impact the symptom experience, management strategies and outcomes (Dodd, et al. 2001, p, 671). Therefore, the environmental domain located within the SMT promote the evaluation and understanding of how individual’s culture and health beliefs impact their perception of symptom experience, strategies and outcomes among diverse populations. For example, Latinos may perceive their symptom in a culturally specific way that differs from the provider understanding. Most importantly when the patients’ perception of a symptom differs from that of the provider than health disparity may develop (e.g., low adherence, negative outcomes; Humphreys, et al. 1999; Fagerhaugh & Strauss, 1977).

Finally, the effectiveness of an intervention can be demonstrated when NES/LEP Spanish predominant Latinos report in culturally specific ways and then have those symptoms assessed in an environment or “condition” where the provider does not speak Spanish or understand the cultural specify ways Latino may report their symptoms (Barakzia et al., 2007; Dodd, 2001, p. 671; Humphreys et al., 2008). Finally, Heilemann, et al., (2004) investigated Latinos’ beliefs regarding the causes of their depression. The authors found that environment domain factors discussed in SMT (e.g., language spoken), and health and illness domain (e.g., risk factors such as distress related to immigration status) were associated with depression among Latinos ( p. 190-91).

The concept of *adherence* is presented in SMT as being linked to symptom management

strategies and outcomes (Dodd et al., 2001). In SMT, *adherence* refers to whether the provider actually prescribed a strategy for an individual (Humphreys et al., 2008; Linder, 2010). *Non-adherence* refers to a prescribed strategy that is not implemented by the individual either because the prescribed strategy was too cumbersome to be implemented or are inconsistently implemented (Dodd, 2001; Humphreys' et al., 2008).

Symptom outcomes result from a dynamic that involves both symptom experiences and symptom management strategies (Dodd et al., 2001). In SMT *outcome* refers to (a) a change occurring in a symptom (e.g., whether the symptom has improved or worsened) (b) how often the symptom manifest (e.g., the symptom's intensity), and (c) how much suffering the symptom causes the individual and the individual's family (Humphreys et al., 2008). Finally, Dodd et al. note that the concept of symptom status outcomes incorporates seven factors: "functional status, emotional status, self-care, cost, quality of life, morbidity and co-morbidity, and mortality" (2001, p. 670).

The existing SMT will be used to inform the design, investigation and the analysis of the study findings. As in all interpretive studies, theory takes a sensitizing rather than a guiding role in this research. A diagram that illustrates how SMT will be used to augment the proposed study is presented in Appendix E. In this proposed study, I will collect data to aid in clarifying, expanding and articulating key concepts and relationships as discussed in the SMT.

### **SPECIFIC AIMS AND RESEARCH QUESTIONS**

This dissertation describes the findings of interviews with Spanish speaking Latinos immigrants with gastrointestinal illness. This project, aimed at increasing knowledge about Latino patients' illness experiences in their attempts to inform health care providers of symptoms of abdominal



pain. The study elicited patients' perspectives on what might improve these patient-provider encounters enabling and facilitating investigation of new methods for improving care provided to this population. The identified aims used in this study were (a) to examine how, **from the patient's perspective**, receipt of health care for GI illness management proceeds in situations of language discordance; (b) to examine how, **from the patient's perspective**, barriers to and aids for communicating illness concerns may manifest in situations of language and cultural discordance; (c) to examine how **patients cope with communication barriers** in managing GI illness; (d) to examine **how Latinos report GI symptoms** in the presence of language discordance; and finally, (e) to collect data on symptom reporting in the context of family among NES-LEP Latino immigrants—data that will serve to clarify the key concepts and relationships in the Symptoms Management Theory (SMT).

As a Latina researcher, my everyday experiences were similar to those of the Latinos I investigated. I shared their culture and language identities therefore I was able to experience a deeper understanding of Latinos culture and language that are often unavailable to researchers from cultures different than those of their subjects (Benner, 1994; Flores, Abreu, Schwartz, & Hill, 2000; Zinn, 1974). For example, in the current circumstances of immigration reform, as an insider I was able to connect with Latino community leaders (Priest, Nuns), gain entrée to the undocumented Latino immigrants and establish trust, due to values and beliefs in common (Rehm, 2003; Zinn, 1974).

As an insider, I was situated in a position that allowed me to recognize and have a better understanding of the cultural nuances of the colloquial, idiomatic, and other non-standard forms of discourse uttered by Latinos—nuances that may be overlooked by an outsider or non-native

researcher ( Zinn, 1974, p. 212). The trust between myself and the Latinos resulted in stories that represented the voice of the population being studied (1974). For example, respondents revealed the essence of a problem being studied and provided complete descriptions of the problem (Parades, 1977). Finally, due to trust between myself and the Latino immigrants it was very likely that the “attitudes and opinions” recorded in the narrative data accurately reflected the attitudes and opinions expressed by this population (Parades, 1977, p. 29).

Although being an insider opened up possibilities (e.g., access to an understudied population), status as an insider was at times constraining. For instance, being an insider necessitated that I continuously negotiate and compromise with participants (Zinn, 1974). One example was that Latinos expected me to share cultural meal which often took several hours out of my research day. As an insider I felt overwhelmed by the responsibility of spending a great deal of personal time with informants as it seemed to slow down the research process. At times, I thought I might limit my personal time with participants and turn my focus towards recruiting this hard to reach population. However, I was acutely aware that I could not exploit Latino immigrants and maintain the rigor of my research (1974). Lastly, my hope is that the findings of this study will provide valuable insight into the nature and effects of language discordance in relation to communication of symptoms and health concerns. The exploration of meaning of Latinos’ lived experience of reporting abdominal pain posed four research questions discussed in the following section.

### **Research Questions**

1. What language and cultural barriers do NES/LEP Latinos with abdominal pain experience when communicating their symptoms to NSS providers?

2. What cultural understandings of abdominal pain do Latino patients express in the symptoms descriptions that these patients communicate to health care providers?
3. What are NES/LEP Latinos' perceptions of the GI illness-related health care that they receive from NSS providers?
4. What strategies do Latino patients use to communicate pain and health concerns across language and cultural discordance?

## Chapter 2

### Review of Literature

Abundant research shows that *language discordance*—defined as differences of language and culture between patients and their health care providers—often results in disparities of health care delivery and health status (Flores, Abreu, Olivar, & Kastner, 1998; Pérez-Stable, Nápoles-Springer, & Miramontes, 1997). Among important areas of clinical interest for caregivers, researchers, and policy makers are the effects of language discordance on health care disparities experienced by Latinos with gastrointestinal (GI) illness. However, to date little research has examined this issue. Although GI disease is one of the most common health conditions occurring in the United States, to date little research has examined the effects of language discordance on Latinos presenting with this disease. The focus of my dissertation is how language discordance affects Latino immigrants seeking health care for treatment of symptoms of GI illness; this present review of literature examines several leading studies on Latino GI illness and on related clinical studies that illuminate the discussion of language discordance as experienced by Latinos.

For health care providers and researchers concerned with Latino immigrant health, an understanding of the ways in which language discordance contributes to health and health care disparities requires examination of several language-related issues: (a) Latino population demographics pertinent to health care disparities; (b) Latino health and health care issues in general (c) Latino sociocultural factors that contribute to health care disparities; and (d) possible mechanisms and processes by which language discordance contributes to Latino health care disparities. Here we note that language discordance

affects Latinos in a variety of ways and in a variety of clinical dimensions. For example, language discordance can render access to care, diagnosis, and treatment inadequate or inappropriate (Garrett, Forero, Dickson & Whelan, 2008). In the following sections of this review of literature we will examine language discordance with regard to Latino GI illness in term of the four language-related considerations described above. Having gained an understanding of these four considerations—especially as they pertain to GI illness—providers and researchers will be able to take steps to rectify the root causes of language-related health care disparities as these root causes manifest in the Latino population in the United States.

### **Scope of Research Included in the Review**

This review of Latino health literature concerns the multifaceted influence of language discordance in clinical contexts. In particular, the review examines relationships between health, language, and culture as these phenomena pertain to health care disparities experienced by Latino immigrants. The review includes both theoretical and empirical studies and discusses, from epidemiologic and clinical perspectives, (a) how language discordance adversely affects Latino health and health care and (b) the influence of race–ethnicity on the reporting and presentation of symptoms—especially regarding gastrointestinal (GI) illness experienced by Spanish-speaking and LEP Latino immigrants.

### **Literature Search Strategy**

The availability of abundant information on Latinos enabled a search that focused on Latino health care disparities directly related to language and cultural discordance. The search sought both quantitative and qualitative research published during the past ten

years. This strategy elicited a variety of types of studies, such as cross-sectional surveys and descriptive ethnography (see Table 1: Literature Search Strategy).

Table 1: Literature Search Strategy

Database (last 10years)	Search Terms	Initial Result	Narrowed abstract	Selected for reading
Pubmed 1	Culture Language	4820	32	15
Pubmed 2	Interpreter Hispanic	3200	22	10
CINHAL	Provider stress	2	2	2
CINHAL	Interpreters acute care	80	19	10
PsychInfo	Health care disparities	2800	25	10?
Cochrane	Non-English patients	270	10	2
Selected References	N/A	15	11	9

### **Latino Immigrant Demographics**

According to the US Census Bureau (BOC, 2010, 54.5 million Latinos lived in the United States (Ennis, Vargas, and Albert, 2010); in that same year, 11.4 million Latinos resided in California (Ennis, et al., 2010). The number of Latinos living in the US is steadily rising. For example, by the year, 2060 it's estimated that 119 million Latinos will reside in US (Colby and Ortman 2014). Here it is useful to consider what is meant by the term "Latino," one of several inconsistently defined terms used in the literature to describe the population of interest in this paper.

BOC (2007) defines *Latino* as a person (a) who comes from or who has originated in one of the predominantly Spanish-speaking countries of the Western hemisphere or (b) who has descended from someone of such origin. Researchers use a variety of terms to

describe Latinos; for example, the terms *Latino* and *Hispanic* are often used interchangeably by BOC and researchers (BOC, 2000).<sup>1</sup> Throughout this paper, the term *Latino immigrant* refers to Spanish-speaking immigrants, except when describing a particular Latino subpopulation (e.g., *Mexican American*: a person who resides in the U.S. and who has Mexican ancestry; Rehm, 2003).<sup>2</sup> The terms *undocumented immigrant* and *illegal immigrant* both refer to people who have (a) entered the U.S. without proper authority from U.S. Citizenship and Immigration Services or (b) overstayed visa limitations (Sullivan & Rehm, 2005).

### **Diversity of the Latino Population**

Although many Latinos share commonalities of language, culture, religion, and health beliefs (Borak, Fiellin, & Chemerynski, 2004; Gallo, Penedo, Espinosa, de los Moateros, & Arguelles, 2009), they comprise a heterogeneous population within and across subgroups (Gallo et al., 2009). Latinos can vary in term of multiple sociocultural characteristics: language (BOC, 2000); culture (Barakzai, Gregory, & Fraser, 2007; Leininger & McFarland, 2006) and cultural values (Zoucha & Broome, 2008); religious beliefs (Gallo et al., 2009); educational attainment and socioeconomics (BOC, 2000); and health beliefs (Wisnivesky, 2009) and health literacy (Britigan, Murnan, & Rojas-Guyler,

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<sup>1</sup> BOC explains that the Office of Management and Budget (OMB) “has decided that the term [of choice for Census purposes] should be ‘Hispanic or Latino’. Because regional usage of the terms differs—Hispanic is commonly used in the eastern and southwestern portions of the United States, whereas Latino is commonly used in the western portion—this change may contribute to improved [Census] response rates”. Retrieved from <http://www.census.gov/population/www/socdemo/race/Ombdir15.html> in section D, “OMB’s Decisions.”

<sup>2</sup> In 2006, approximately 30.7 million Americans listed their ancestry as being “Mexican” (BOC, 2006).

2009), to name a few examples. Latinos' demographic heterogeneity may contribute to this population's health disparities (Timmins, 2002). Here it is useful to examine some of the unique characteristics of Latino health before proceeding to consider the influences of sociological factors—especially language discordance—on the health and health care experience of this population.

### **Latino Health and Health Care**

#### **Definitions**

*Health* has been defined as “physical and mental well being” (*Webster’s New World Dictionary and Thesaurus*, 2002, p. 293). Closely related to our consideration of health—and central to an understanding of Latino health—is the phenomenon of health disparity. The term *health disparity* is defined as “differences in the incidence, prevalence, mortality, and burden of disease, and in other dimension of health” as health is experienced across population groups in the United States; in particular, health disparities refer to relative health deficiencies experienced by some groups in contrast with health as experienced by non-Latino Whites (National Institutes of Health [NIH], 2000, p. 7).

A recent survey regarding health status has found that Latinos more frequently report having poor health status than do non-Latino Whites (Bzostek, Goldman, & Peibly, 2007). For example, in comparison with non-Latino Whites, Latinos have higher rates of specific chronic diseases (Clark, Vincent, Zimmer, & Sanchez, 2009), including obesity and diabetes (Clark et al., 2009; Pokas et al., 2008); higher rates of hypertension (U.S. Department of Health and Human Services [DHHS], 2000); and more advanced metastatic colon cancer at younger ages (Stefanidis et al., 2006). However, few studies



have explored how specific health outcomes correlate with the overall health status of Latino patients—a topic we return to later in this paper.

### **Understanding Latino Health**

Research findings and conclusions on the health status of Latinos are sometimes ambiguous and even, in some instances, contradictory (Gallo, 2009). For example, first generation (i.e., non-US born); Latino immigrants have worse overall health when compared to second generation Latinos (US born with at least one parent not born in the U.S.); and non-Latino whites (Taningco, 2007). Conversely, studies show that first generation Latino immigrants experience better health with regard to diabetes and high blood pressure when compared to second generation Latinos (Taningco, 2007; Franzzini, Ribble, & Keddie, 2001).

Another surprising finding regarding Latino health is the *Latino epidemiological paradox*—which refers to the discovery that, contrary to assumptions based on Latinos' low socioeconomic status, this population has lower mortality rates than does the non-Latino White population (Gallo et al., 2009; Lara, Gamboa, Kahramanian, Morales, & Hayes-Bautista, 2005). This finding is counter to the expectation suggested by otherwise well-documented relationship between poor health and low socioeconomic status (Mitchell & Lassiter, 2006.) Yet another surprising finding regarding Latino health is that despite Latinos' lower-than-expected mortality rates, they describe their health status as “poor” more often than do non-Latino Whites (Dubard & Gizlice, 2008).

### **Health Care Disparities**

Health care disparities across populations have been widely recognized. *Healthy People 2020*—the articulation of America's ongoing national health initiatives since

1990—has outlined goals that include eliminating health care disparities and increasing years of good health for all affected populations (Wagener, Molla, Crimmins, Pamuk, & Madans, 2001). These outlined goals as discussed above encompass “ the establishment of national standards for Culturally and Linguistically Appropriate Services” with the central objective being to provide appropriate health care to all patients (U.S. Department of Health and Human Services [DHHS], 2010). Spanish-speaking Latinos have greater health care disparities than do their English-speaking Latino counterparts (Flores, 2006; Gallo, 2009). For example, in comparison with non-Latino Whites and English-speaking Latinos, Spanish-speaking Latinos

- are less likely to utilize a usual source of health care service (Derose & Baker, 2000);
- are less likely to utilize preventive care (Lopez-Quintero, Berry, & Nuemark, 2009);
- are less often understood by their providers (Flores, 2005);
- experience a higher frequency of inadequate and delayed health care (Baker, Parker, Williams, Coates, & Pitkins, 1996);
- are less likely to receive an accurate clinical diagnosis (Minsky, Vega, Miskimen, Gara, & Escobar, 2003);
- have less access to pharmacies and medications (Coffman, Shobe, & Connell, 2008);
- more frequently experience delays in pain management (Todd, Samaroo, & Hoffman, 1993) and delayed GI care (Wu, Banks, & Conwell, 2009); and, not surprisingly,

- feel less satisfaction with care overall (Carrasquillo, Orav, Brennan, & Burstin, 1999; Lee, Batal, Maselli, & Kutner, 2002).

We will return to the topic of health disparities later in this paper when we discuss Latino health disparities in the context of language discordance (see section “Language and Latino Health and Health Care”).

### **Definition, significance, and prevalence of GI illness**

The term *gastrointestinal* refers to “the stomach and intestines” (*Dorland’s Pocket Medical Dictionary*, 1982, p. 292). The term *illness* refers to the “condition of being in poor health; sickness or disease” (*Webster’s New World Dictionary and Thesaurus*, p. 316, 2002). Studies show that providers’ offices are inundated by patients who present with various GI conditions. In 2010, for example, 51 million people suffering from GI conditions sought care from providers (CDC–National Center for Health Statistics [NCHS], 2012). Furthermore, in 2010, eight million people presented to the ED complaining of GI illness who received a diagnoses of gastrointestinal disease (CDC–NCHS, 2012). Despite the high incidence of GI conditions, few studies have explored how these conditions are experienced by Spanish-speaking Latinos. One recent study, however, has reported that this group of Latinos experiences longer wait times before receiving primary clinical assessment for acute GI symptoms in the emergency room (Wu et al., 2009).

**Diagnosis of GI illnesses.** Although a number of GI illnesses can be diagnosed absent of a patient’s report of symptoms, diagnosis of some GI illnesses requires in-depth knowledge of a patient’s symptom history (Lacy & De Lee, 2005). For example, diagnosis of cirrhosis proceeds from laboratory tests and physical examination (and

without knowledge of symptoms); in contrast, diagnosis of acute abdominal conditions require detailed knowledge of patient symptoms (Jones & Claridge, 2004).

**Some specific gastrointestinal illness.** A number of GI illnesses can put patients at risk for serious complications and/or lead to poor health care outcomes if treatment is delayed or impaired by miscommunication between patients and providers (Diehl, Westwick, Badgett, Sugarek, & Todd, 1993). Few Latino health studies have examined how language and culture discordance can impede assessment and diagnosis of GI symptoms.; however, some relevant investigation have elucidated this issue—for example, studies pertaining to acute abdominal pain, and appendicitis.

***Irritable bowel syndrome.*** *Irritable bowel syndrome* (IBS) refers to a chronic gastrointestinal disorder often characterized by symptoms of abdominal pain and abnormal bowel habits; such habits can include intermittent alternating diarrhea and constipation (Grundmann & Yoon, 2010). IBS, the most prevalent GI disorder diagnosed in the U.S., affects up to 20% of the U.S. population (Gaman, Bucur, & Kuo, 2009). Moreover, IBS accounts for 2.4–3.5 million annual visits to primary providers in the U.S. (Lacy, 2005; Paterson et al., 1999). Patients with IBS account for almost half of all visits to gastroenterologists (Lacy, 2005). IBS is widely viewed as being challenging to diagnose (Paterson, 1999), and, in the context of patient-caregiver language discordance, detection of IBS can be particularly problematic. Because IBS has no definitive physical or laboratory identifiers, diagnosis of IBS is arrived at through exclusion of other diseases—a process that can be costly and frustrating for both practitioner and patient (Barakzai et al., 2007; Lacy, 2005). The cost of treatment and care for individuals with IBS in the U.S. averages \$1.35 billion in direct costs (i.e., patient care) and \$205 million

in indirect costs (i.e., lost wages; Gaman et al., 2009). The impact of IBS on the Latino population is not well quantified or well documented.

***Acute abdomen.*** The term *acute abdomen* refers to "symptoms and signs of intra-abdominal disease usually treated best by surgical operation" (Jones & Claridge, 2004, p. 1219). One disease that often produces acute abdomen is appendicitis. As with IBS, the assessment, diagnosis, and treatment of abdominal pain associated with appendicitis require that providers obtain from their patients a thorough history of symptoms (Flasar & Goldberg, 2006).

***Appendicitis.*** *Appendicitis*, the inflammation of the appendix, is the most common acute surgical emergency of the abdomen (NIH, 2008). Appendicitis has no effective countervailing medical therapy; accordingly, the condition is treated as a medical emergency (Flasar & Goldberg, 2006). However, when surgery is performed promptly, most patients recover without difficulty. On the other hand, delayed treatment of appendicitis may result in infection and gangrene (Flasar & Goldberg, 2006). A patient's prompt communication of appendicitis symptoms is essential for early diagnosis of what otherwise can become a life-threatening condition (NIH, 2008). For clinical diagnosis of appendicitis, a thorough history of the patient's symptoms and a physical examination are often all that are required (Flasar & Goldberg, 2006). Knowledge of two facts—(a) the development of symptoms in relation to the onset of illness and (b) the precise location and severity of patient's pain—facilitates correct and timely diagnosis of appendicitis (Flasar & Goldberg, 2006). Here we note that Spanish-speaking Latino immigrants report that, due to language discordance, they are often unable to describe

symptoms of illness to English-speaking health care providers (Roberts, Moss, Sarangi, & Jones, 2005; Stein, Flores, Graham, Magana, & Willies-Jacobs, 2004).

***Abdominal pain.*** Complaints of abdominal pain are common in all clinical settings in the U.S. and can include acute and chronic abdominal pain. For example, from 1999 to 2008, the number of adults presenting to the ED, with a chief complaint of abdominal pain increased from 5.2 million to 7 million (Bhuiya, Pitts, and McCaig, 2010). In one study, Johnston and Bao (2011) found differences in the initial assessment times in adults presenting to the ED with abdominal pain based on “race/ethnicity, and ability to pay”. Flasar and Goldberg (2006) point out that, in certain situations, abdominal pain may indicate onset of a life-threatening illness. Abdominal pain can be either acute or chronic, depending on its cause.

***Acute abdominal pain.*** The term *acute abdominal pain* generally refers to previously undiagnosed pain that manifests abruptly and is of less than seven days’ duration (de Dombal, 1991). In the general population, abdominal pain continues to be a leading cause of emergency room visits in the U.S. (CDC–National Center for Health Statistics [NCHS], 2011); Yee, Puntillo, Miaskowski, & Neighbor, 2006). Patient–caregiver language discordance can impair diagnosis of abdominal pain and lead to delayed care of Latino patients (Stein et al., 2004). Flasar and Goldberg (2006) have observed that a patient’s self-reported symptoms history can provide advanced warning, informing a provider that a severe, life-threatening abdominal condition is imminent; these warning signs can include fever, vomiting, and constipation. In this light, patients’ ability to communicate with their providers is of paramount importance in securing accurate diagnosis and timely care for acute abdominal pain (Flasar & Goldberg, 2006).

In one observational study, the investigators found that when physicians used patients' reported history and physical examination alone, the physicians were able to correctly differentiate between the different causes of abdominal pain (e.g., organic or inorganic) nearly 80% of the time (Martina, Bucheli, Stotz, Battegay, & Gyr, 1997).

Language discordance is not the only inhibiting factor that affects communication for Latinos. Culture, also, can influence how Latinos report and experience symptoms of illness (Diaz et al., 2009). In the following section we consider several sociocultural factors that have a bearing on Latino health.

### **Sociocultural Factors Affecting Latino Health**

In our discussion of the effects of language discordance on Latino health and health care, it is also important to consider the effects of language-related sociological factors—culture, religion, legal status, socioeconomics, and education—on Latino health. In this section we discuss each of these factors in turn.

#### **Culture and Latino Health**

*Culture* has been defined as “the learned, shared and transmitted values, beliefs, norms, and lifeways of a particular culture that guide thinking, decisions, and actions in patterned ways and is often intergenerational” (Leininger & McFarland, 2006, p.13). As Lasch has noted, “Culture has a vital influence on illness behaviors, health care practices, help-seeking activities, and receptivity to medical care interventions” (2000, p. 18). Culture affects how an individual defines illness, what an individual considers to be appropriate care, and to what degree illness will affect an individual and the individual's family (Barakzai et al., 2007).

**Latino cultural values.** Latinos hold a number of cultural values that are significant in health care communication (Flores, Abreu, Schwartz, & Hill, 2000; Huerta & Macario, 1999). Examples of core cultural values are *familismo*, *personalismo*, and *respeto* (Gannotti, Kaplan, Handwerker, & Groce, 2004). Where Latino core cultural values differ from those of non-Latino providers, these discordances can result in miscommunication that diminishes the quality of diagnosis and treatment (Stein, 2004).

- *Familismo* (importance of family): A shared commitment to an extended “family or group; [this commitment] can result in deferral of important medical decisions to permit consultation with extended family” (Perez-Stable, 1987, p. 217).
- *Personalismo* (friendly conduct): In the context of patient–caregiver relationships, the cultural value of *personalismo* implies that “patient and care giver will [share/form] a warm personal [bond/relationship]” (Perez-Stable, 1987, p. 217).
- *Respeto* (respect): *Respeto* refers to the “highly esteemed cultural value of respect and mutual deference” (Anez, Silva, Paris & Bedregal, 2008, p. 156).

**Culture, Acculturation, and Latino Health.** In today’s multicultural world—increasingly influenced by mass communication and market forces—cultural isolation and community cultural homogeneity are sociological rarities (Lara, 2005). Consequently, for the individual, one’s personal cultural identity is seldom homogeneous, but rather is a heterogeneous blend of multiple cultural influences (Lara, 2005). For immigrants, relocation from one country to another adds an additional variable to cultural identification heterogeneity. Moreover, when people have been forcibly compelled to



migrate from their country of origin—for economic, social, or political reasons—the experience of acculturation in their adoptive country is often psychologically traumatic (Salgado de Snyder, 1987). *Acculturation* refers to a complex concept well described in the literature (Berry, 2001)—the process by which an immigrant adopts “the attitudes, values, customs, beliefs, and behaviors of the dominant culture” (Clark & Hofstede, 1998, pp. 53–54; LaFromboise & Gerton, 1993). The trauma of acculturation influences all aspects of immigrants’ lives—including their health and engagement in health care (Lara, 2005). In this regard we turn to consider the impact of culture and acculturation on four dimensions of Latino health: health status, health belief and understanding, communication about health, and engagement in treatment and care.

***Impact of culture on health status.*** The degree of an individual’s acculturation can affect a person’s health status (Lara et al., 2005). Greater acculturation has been associated with better or worse overall health status among minorities; such association depends on the specific health outcome being examined (Edelman, Christian, & Mosca, 2009).

***Impact of culture on health belief and understanding:*** Health belief as described in the *health belief model* (HBM), are shaped by several assumptive considerations that influence the judgments regarding a potential or actual illness: (a) one’s *susceptibility* to the illness, (b) the anticipated *severity* of the illness, (c) the anticipated *benefits* from engaging in treatment, (d) assessment of potential or actual *barriers* to treatment (e.g., financial, logistical, social, medical), and (e) the general sense of *self-efficacy* that one feels with regard to one’s health (Janz & Becker, 1984). All of these considerations influence how one experiences illness and engages in treatment. For example, a person’s

health beliefs can influence how that individual describes illness symptoms to providers (Barakzai et al., 2007; Calvillo & Flaskerud, 1991) and how the individual copes with symptoms of disease (Abraido-Lanza, Vasquez, & Echeverria, 2004).

Health beliefs are influenced by one's cultural experience and identity (Calvillo & Flaskerud, 1991; Lemely & Spies, 2015), as well as by the degree to which a person has become acculturated to an adoptive culture (Edelman et al., 2009). For example, many Latinos accept and value the experience of suffering and regard suffering as an inevitable part of life (Calvillo & Flaskerud, 1991). Furthermore, a patient's health beliefs may not correspond with those of the patient's care providers (Blumhagen, 1980). In this regard, research has documented health-belief incongruities between Latino patients and their providers relative to the cause(s) and interpreted meanings of illness and symptoms. Wisnivesky et al. (2009) has reported on health-belief incongruence in the case of LEP Latino patients with asthma; and Philis-Tsimikas et al. (2004) have reported on health-belief incongruence in the case of Latinos patients with diabetes. Similarly Kosko and Flaskerud (1987) have reported that health belief incongruence between Mexican-American patients and their providers is a contributing factor in chest-pain symptom description and consequent treatment.

***Impact of culture on perception and interpretation of symptoms.*** Two ways in which culture can have a profound effect on diagnosis and treatment are in patients' perception and description of symptoms. As discussed earlier, this effect is particularly significant for conditions in which patient history is the primary means of diagnosis, such as with irritable bowel syndrome (Barakzai et al., 2007; Diaz, 2009; Minsky et al., 2003; Moldavsky, 2004). In addition, culture shapes the ways in which patients express,

experience, and cope with their feelings of distress, and thereby, how patients describe and explain their symptoms (Moldavsky, 2004). Few studies have examined cultural norms in the reporting of GI symptoms among Spanish-speaking Latino immigrants. However, studies show that when cultural discordance is not considered during communication with Latinos, clinical histories are unreliable, and this unreliability significantly impedes the diagnostic process for this population (Rueda-Lara, Burchert, Skotzo, & Clemow, 2003).

***Impact of culture on communication about health.*** We have mentioned earlier that one's cultural identity influences how one communicates about health. In this regard, Latinos may describe symptoms of illness in culturally specific ways (Pachter, 1994). For example, they may use metaphors (Dobkin, de Rios, & Achauer, 1991) to describe their illness (e.g., using phrases such as "cold bones" to describe symptoms of IBS; Barakzai et al., 2007, p.263). Furthermore, the culturally influenced linguistic conventions by which a group communicates about health in turn affects the group's health care outcomes (Rueda-Lara, et al., 2003). Ultimately, the group's health care outcomes—the endpoint experiences of a group's encounter with health care—play a major role in determining the group's overall satisfaction with the health care that the group receives (Morales, Cunningham, Brown, Liu, & Hays, 1999). Thus, satisfaction with care has been found to be closely linked to better health care outcomes among Latinos (Morales et al., 1999). In this regard, the relationship between language discordance and satisfaction with healthcare is clear: Latinos who speak fluent English report greater satisfaction with care than do non-English-speaking (NES) Latinos (Morales et al., 1999).

In addition to direct influences of culture on health care outcomes, culture can also have indirect but nevertheless significant influences. For example, culture affects the way in which Latinos report depression—and, as a consequence, the way in which health care providers diagnose the severity of Latino patients' reported symptoms of depression (Minsky, 2003). Thus Latinos' descriptions of symptoms of psychosis are sometimes misdiagnosed as descriptions of symptoms of depression by providers who may be unfamiliar with Latino culture. Conversely, the descriptions by non-depressed patients of their normal psychological experience may be misinterpreted by providers as being indicative of depression (Minsky, 2003).

Although the influence of culture on patients' reporting and diagnosis of gastrointestinal illness and mental illness is not well studied in the Latino population, two studies have proposed associations between (a) symptoms of abdominal pain and reported symptoms of depression as experienced by Latinos (Magni, Rigatti-Luchini, & Merskey, 1992) and (b) chronic abdominal pain and suicidality as experienced by Latinos (Magni, Rigatti-Luchini, Fracca, & Merskey, 1998). Given the paucity of studies investigating the role of culture on the reporting of gastrointestinal illness symptoms among Latinos, and the possible negative ramifications of the consequent lack of clinical knowledge, more studies investigating this phenomenon are warranted.

***Impact of culture on engagement in treatment or care.*** As noted earlier, cultural discordances can lead to negative health care outcomes among Latinos. Possible negative outcomes include poor management of symptoms of illness (Calvillo & Flaskerud, 1991) and low compliance with medication regimens and care plans (Wisnivesky et al., 2009). Health beliefs also influence patients' responses to preventive screening

recommendations (e.g., colorectal cancer screening; Gao, Burke, Somkin, & Pasick, 2009; Coronado, Petrik, Spofford, Talbot, Hoai Do, & Taylor, 2015). Latinos' health beliefs can influence their health-seeking behaviors (Roberts, Kent, Prys, & Lewis, 2003). For example, Latinos often seek informal sources of care, such as family and friends, before consulting with a provider (Cabassa & Zayas, 2007; Im, Guevara, & Chee, 2007). Studies show that Latinos sometimes self-medicate with alternative medicine (e.g., herbs) prior to seeking formal care for GI symptoms (Graces, Scarinci, & Harrison, 2006). Moreover, Latinos are less likely than non-Latino Whites to seek care for bowel complaints (Zuckerman, Guerra, Drossman, Foland, & Gregory, 1996). Though scant data exists regarding Latinos' health-seeking behaviors for GI symptoms in particular, studies do indicate that the degree of Latinos' acculturation may predict their health care utilization in general (Lara, 2005).

***Impact of acculturation on health care utilization.*** Acculturation can influence health care utilization in several ways. For example, studies show that the degree of one's acculturation is associated with how often one utilizes preventive health care services. Latinos who are more acculturated to the dominant culture are more likely to participate in preventive screening for cholesterol and blood pressure than are Latino who are less acculturated (Jurkowski & Johnston, 2005). The degree of an immigrant's acculturation can also affect both access to care (Breen, Rao, & Meissner, 2008) and health beliefs and practices concerning seeking care for illness (Edelman, 2009). For example, Latinos who have acculturated to greater degrees may be less likely to have health beliefs that differ from those held by U.S.-born Latinos (e.g., with regards to the benefits of seeking preventative care; Xu & Borders, 2008). Conversely, minimally

acculturated Latinos may share health care beliefs that may create barriers to their receipt of care; for example, they may fear preventive screening for cardiovascular disease (Edelman, 2009), and they may delay identifying, preventing, and seeking help for symptoms of acute myocardial infarction or heart attack (Henderson, Magana, Korn, Genna, & Bretsky, 2002).

### **Religion and Latino Health**

*Religion* has been defined as “the belief in and worship of God or gods” (*Webster’s New World Dictionary and Thesaurus*, 2002, p. 539). For many Latinos, religion influences their perception of medical encounters (Reyes-Ortiz, Rodriguez & Markides, 2009). For example, when some Latino patients perceived they were not given adequate information about their illness from their provider these patients’ requested that others (e.g., a family member) pray for their healing (Reyes-Ortiz et al., 2009). Moreover, religious beliefs may influence how Latinos cope with illness (Rehm, 1999), and how they inform providers of their symptoms (Kosko & Flaskerud, 1986; Reyes-Ortiz, 2009).

### **Legal Status and Latino Health**

The Pew Hispanic Center recently reported, 6.1 million undocumented Mexican immigrants resided in the U.S. (Passel, Cohn & Gonzalez-Barrera, 2013; Capitman, Traje, & Tania Pacheco, 2009).<sup>3</sup> Although declining in numbers, Latinos from Mexican origin represent over 50 percent of the undocumented immigrants residing in the United

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<sup>3</sup> For example, California’s San Joaquin Valley is home to approximately 280,745 undocumented Latino immigrants (Capitman et al., 2009). In the Valley’s largest city, Fresno, 44% of the population is undocumented Latino immigrants (BOC, 2003).

States (Edwards, 2014). Undocumented Latinos are reported to suffer higher rates of health care disparities than do documented Latino immigrants (Capitman et al., 2009).

**Legal status and health care disparities.** Studies show that undocumented Latinos have low rates of health care use; these low-use rates are associated with fear of deportation (Rehm, 2003). Undocumented Latinos experience health care disparities more frequently than do their documented Latino counterparts. These disparities include decreased access to care (Stein, 2004), lower rates of usual source of care (Beal, Hernandez, & Doty, 2009), low use of health services (Rodriguez-Galan & Falcon, 2009), and poor experiences with care (Ortega et al., 2007).

### **Socioeconomic and Latino Health**

Although Latinos are represented in the entire socioeconomic spectrum, as a group they are reported to have the lowest SES of all major subpopulations in America (Gallo, 2009). In 2008, Latinos' median household income was \$37,913 (BOC, 2009); in that year, the national median was \$50,530 (BOC, 2009). Moreover, Latino subgroups vary in their economic standing. In comparison with all other Latino groups, Mexican Americans suffer the greatest economic hardship; in contrast, Cuban Americans generally have the highest SES of all Latino subgroups in the United States (BOC, 2000d; Cortes, Mulvaney-Day, Fotuna, Reinfeld, & Algeria, 2009).

**Health insurance.** A key aspect of socioeconomic status relative to health care is possession of health insurance. Fewer Latinos have health insurance than is the norm for other racial and ethnic groups (Bustamante et al., 2009, Capitman, 2009; Gaskin & Hoffman, 2000). The BOC has recently reported that 34% of U.S.-citizen Latinos born outside the U.S. lack health insurance; in comparison, 10% of non-Latino Whites lack

health insurance (Bustamante, 2009). In another survey, 32.2% of Latinos reported being uninsured; in comparison, 12.0 % of non-Latino Whites reported being uninsured (Carrasquillo, Himmelstein, Woolhandler, & Bor, (1999). Lack of health insurance is associated with decreased access to health care and decreased usual source of health care (Beal et al., 2009; Bustamante, 2009), and it comes as no surprise that Latinos who have health insurance are more likely to experience good health care than are uninsured Latinos (Perez, Ang, & Vega, 2009).

***Undocumented Latinos and health insurance.*** In general, fewer undocumented Latino immigrants have health insurance than is the norm for their documented Latino counterparts (Carrasquillo, Carrasquillo, & Shea, 2000; Rodriguez, Bustamante, & Ang, 2009). Capitman and colleagues (2009) point out that currently in the United States undocumented Latinos are excluded from subsidized health insurance, which further reduces this population's access to care. In the San Joaquin Valley, for example, the Medically Indigent Services Program (MISP) is offered to Latino immigrants. However, this program has strict requirements for participation including proof of citizenship and income requirements both which are exclusionary for undocumented immigrants. In 2009, only 10% of Fresno's undocumented immigrants reported having insurance coverage and or utilizing a usual source of health care (Capitman, 2009).

### **Summary of Studies of Sociocultural Factors Affecting Latino Health**

The interrelated influences of sociocultural factors on Latino health (Cabassa & Zayas, 2007; Im, et al., 2007; Rehm, 2003); and on Latino health care disparities are well documented. Latino health care associated with sociocultural factors including patient-provider culture discordance has also been extensively studied (Flores, 1998). Although



these Latino health studies have several strengths, weaknesses in the studies' design (e.g., use of a statistically inadequate number of male participants render their findings questionable Pachter et al., 2002). The following discussion reviews strengths and weakness of leading studies that have examined effects of sociocultural factors on Latino health.

**Proportionality and consistency of diagnoses—Major depression.** Diaz and colleagues (2009) used structured interviews to examine (a) whether Latinos had disproportionate rates of clinical diagnoses of major depression and (b) whether diagnostic patterns were consistent with patient descriptions and information from medical records. One of the strengths of this study was its contribution to an otherwise limited body of knowledge regarding the impact of sociocultural factors on diagnostic accuracy. In addition, the study's findings supported previous research (Minsky, 2003). Although this investigation by Diaz et al. had strengths, the study also had several limitations. For example, other investigations have shown that a study's use of structured interviews can potentially introduce bias into the ways in which Latinos respond to questions and thereby can diminish the validity of the study outcomes (Bzostek, Goldman, & Pebley, 2007; Gao et al., 2009; Viruell-Fuentes, Morenoff, Williams, & House, 2010); such influences may have arisen from use of structured interviews in the study by Diaz et al. In addition, the study's small sample size ( $N = 259$ ) precluded analysis of participants according to nationality. Also the study's sample consisted only of Latinos who were either English-speaking or bilingual and who had severe depression or psychotic symptoms; these selection constraints might have further limited the generalizability of the study's findings.

**Presentation of symptoms and diagnosis—Psychiatric illness.** Minsky and colleagues (2003) examined psychiatric services data provided by a large behavioral health service in New Jersey. The investigators sought to determine whether there are differences in the ways that Latino, European American, and African American psychiatric patients experience and present symptoms and are diagnosed with illness. The study's strengths included its contribution to a limited body of knowledge in an understudied population (i.e., Latinos) and the study's contribution to data regarding the influence of sociocultural factors in the reporting of symptoms by Latinos. Other strengths include the study's large sample size ( $N = 19,219$ ) and the use of Basis-32 self-report questionnaire—an instrument previously validated for use with multiethnic patients including Latinos. On the other hand, the Minsky et al. study also had limitations. For example, the sample consisted of patients from mental health clinic settings whose healthcare experience could not be easily generalized to other populations. Moreover, the service system data set used in the study is known to often omit data collection on nationality and acculturation. Therefore, the researchers could not assess the participants' nationalities or degrees of acculturation—information that could have distorted the outcomes of the study findings (Minsky et al., 2003).

**Perceptions, beliefs, and healthcare practices—Asthma.** Pachter and colleagues (2002) conducted a community asthma survey. This study's sample consisted of 160 Latinos (i.e., Puerto Ricans, Mexican Americans, Mexicans, and Guatemalans). Most of these respondents were women who were approximately 40 years of age. The study's strength was its contribution to clinical understanding of the perceptions and health care practices of an understudied, diverse subpopulation of Latinos. For, example, the authors

found that four Latino groups shared similar beliefs pertaining to asthma (e.g., beliefs concerning weak lungs and air pollution). However, the authors also discovered that there were differences between Latino groups regarding beliefs surrounding the causes, symptoms, and treatments for asthma. However, the study also had several limitations. First, the study's findings could have been influenced by the fact that the sample was a community sample rather than a clinical sample. In this regard, respondents from the community sample may not have received health education about asthma's symptoms—a design deficit that could have impacted the study's findings. Second, all the sample's participants were Latinos, and therefore the study's findings could not be generalized to other populations. Third, because the study did not include data on non-Latino groups, it could not be determined whether reported beliefs were specific to the Latino population. Finally, the fact that the majority of participants were female further limited the study's generalizability.

**Acculturation—Cardiovascular disease risk.** Edelman and colleagues (2009) conducted a cross-sectional study of minority participants enrolled in the Family Intervention Trial for Heart Health (FITHH), a one-year study sponsored by the National Heart, Lung, and Blood Institute. Among the Edelman et al. study strengths was its use of a diverse sample of minorities. However, several limitations reduced the validity of the study's findings. For example, because the subgroup sizes were small, the statistical power of subgroup analyses was limited, and therefore researchers could not identify differences in cardiovascular disease (CVD) risk factors among subgroups. Other limitations included and the fact that the sample consisted mostly of women from the Dominican Republic who had been residing in the United States for more than 10 years.

Thus, minimally acculturated Latinos groups and other Latino sub-groups who may have had different beliefs and barriers to CVD care were not represented in the sample, limiting the study findings' generalizability to other populations.

**Congruence of symptoms and diagnosis—IBS.** Barakzai and colleagues (2007) conducted a retrospective chart review to explore whether the symptoms reported by Mexican-American patients diagnosed with irritable bowel syndrome (IBS) actually satisfied the then current then diagnostic criteria. This study had strengths, including its contribution to an otherwise-limited body of knowledge regarding the reporting of GI illness (specifically, IBS) symptoms by Spanish-speaking Latinos. On the other hand, several weaknesses reduced the validity of the study findings. For example, the study's design involved a retrospective chart review, and therefore researchers were unable to differentiate between cause and effect (i.e., whether language discordance caused atypical reporting of IBS symptoms). Other weaknesses included the study's small sample size ( $N = 139$ ), lack of sample diversity (i.e., most sample participants were Mexican-American and female), and limited geographic scope (i.e., all patients were recruited from two hospitals in California's Central Valley). Therefore, this study's conclusions could not be generalized to other populations, settings, or geographic locations.

The several studies cited in this Summary section have illuminated our understanding of sociocultural factors on Latino health. Taken together, the studies indicate that these factors are multiple, interrelated, and complex. We have noted that in several instances the findings of these studies could not be generalized to other populations because of (a) researchers' use of various study designs, (a) the diversity of the population being studied, (a) the lack of appropriate comparison groups, and (a) small sample sizes; for

these reasons, the validity of some of the studies' findings was questionable.

Nevertheless, the studies substantiate a conclusion that the influences of sociocultural influences on Latino health are significant in their degrees of influence and therefore deserve further attention in both research and treatment contexts

### **Language Discordance and Latino Health Care**

#### **Definitions**

*Communication* has been defined as “the process by which information is exchanged between individuals through a common system of symbols, signs or behavior” (*Webster’s New World Dictionary and Thesaurus*, 2002, p. 123). Communication can be impaired when patients and providers do not share a common primary language. In this light, it is not surprising that Latinos report better health functioning when they are cared for by providers who speak their language (Borak et al., 2004; Perez-Stable, Napoles-Springer, & Miramontes, 1997). The effectiveness of communication in health care settings is in many ways determined by an individual’s communicative language proficiency.

*Communicative language proficiency* refers to one’s knowledge and ability to utilize both oral and written language (Canale, 1983; in before Bagarić & Djigunovi, 2007). *Limited English proficiency* (LEP), is defined as having a limited or total inability to speak and write in English and to comprehend English (in listening and reading) to a degree that inhibits effective interaction with health care providers (Jacobs, Chen, Karliner, Agger-Gupta, & Mutha, 2006). Non-native-English (NES) speakers—including NES Latinos—may be *English language learners* (ELLs)—those whose primary language is other than English (Johnson, 1983). *Monolingual Spanish speakers* are individuals who speak Spanish as their primary language. As a population, Latinos vary in their English

proficiency that they are able to utilize in their communications with providers (Timmins, 2002), the impact of communicative language proficiency on Latinos' reporting of health care outcomes, such as those related to GI disorders, is not well understood.

**Language proficiency and health care disparities.** The BOC recently reported 21% of the total population over age 5 (more than 61.8 million people) claimed that they spoke a language other than English at home (Carmota and Zeigler, 2014). Furthermore, over 25 million Americans reported they had LEP (Camarota, et al., 2014). Latino patients with LEP represent a wide-range of English language proficiencies (i.e., very low to high) in their encounters with health care providers, and these patients may be reluctant to reveal their failures of understanding. As a result, providers may overestimate Latinos' ability to speak English, thereby increasing risks shared by patient and providers of miscommunication, associated with medical error, and health care disparities overall.

**Latino language discordance and health care disparities.** As Timmins (2002) notes, the relationship between communication and health care disparities is complex, having multiple interrelated factors. In this regard, Spanish-speaking Latinos are more dissatisfied with provider communication than are their English-speaking counterparts (Morales, 1999). Spanish-speaking Latinos also receive less health care information about chronic disease (Gonzalez, Vega, Rodriguez, Tarraf, & Sirbney, 2009) and a lower quality of care (Baker et al., 1996). Not surprisingly, Spanish-speaking Latinos also experience poorer health care outcomes (Sherraden & Barrera, 1996).

**Latino language discordance and communication about symptoms.** Few studies have investigated the impact of communicating GI symptoms across language and culture in this population. However, studies show that ineffective communication between

providers and patients leads to health care disparities including possible increased wait times in the assessment of GI symptoms in the emergency room (e.g., appendicitis) in Latinos (Wu, 2009).

### **Health Literacy**

*Health literacy* (HL) has been defined by the Institute of Medicine (2004, p. 1) as “the degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions” (*Healthy People*, 2010; see also Agency of Health Research and Quality, 2007). *Healthy People 2010* defines *proficiency in health literacy* as a person’s capacity to obtain, process, and understand basic information and services (Institute of Medicine, 2004, p. 32). As a population subgroup, Latinos have a lower rate of health literacy than do non-Latino Whites (Britigan et al., 2009). Thus, in one survey of health literacy, approximately 41% of Latino adults were found to have “below basic” understanding of health information (NCHS, 2007). Negative health care outcomes are associated with inadequate health literacy (Hahn & Cella, 2003; National Council of La Raza, 2009). Latinos who have low HL report poorer health status (Flores, 2006) and have higher rates of readmission to the hospital than do non-Latino Whites with adequate HL (Baker, Parker, Williams, & Clark, 1998; Britigan, 2009; NCLR, 2009).

### **Language Discordance and Latinos’ Experience of Health Care**

Communicating health care information between individuals who do not share a common primary language is a significant health care problem for Latino patients. Latinos who attempt to access the health care system often report being unable to communicate effectively with their health care provider (Timmins, 2002). Furthermore,

such communication failures are not one-sided: several studies have found that inadequate communication between providers and Latino patients often limits providers' understanding of their patients' reported symptoms (Cristancho, Garces, Peters, & Mueller, 2008; Diaz, 2009; Minsky, 2003). Moreover, evidence suggests that language discordance between Latino patients and non-Spanish-speaking providers (e.g., nurses, physicians) can detract from the quality of interviews about the patients' symptoms (i.e., can result in miscommunication, misdiagnosis, and improper treatment of illness; Minsky, 2003; Diaz, 2009). However, merely eliminating language discordance as a single isolated measure may be insufficient by itself to assure good care. For example, when interviewing Latinos patients about their symptoms in their native language (Spanish) these patients appeared to be psychotic but when the same patients were interviewed in-English they reported little or no psychotic symptoms (De Castillo, 1970). Therefore, identifying other barriers to communication of symptoms in health care environments is vital for delivering appropriate care (Diaz, 2009; Minsky, 2009) and thereby achieving optimal health care outcomes for this population (Malgady & Costantino, 1998).

The adverse ramifications of patient-provider language discordance in clinical settings are well documented in the literature (Rueda-Lara et al., 2003). These ramifications include (a) reduced intrinsic (personal) motivation (Seijo, Gomez, & Freidenberg, 1991); (b) low use of health care services; (c) limited or inaccurate patient-provider communication regarding adverse health conditions (Rueda-Lara, 2003); (d) inadequate adherence to care regimens and other aspects of treatment (Coffman et al., 2008); (e) suboptimal health care outcomes (Sherraden & Barrera, 1996); and (f) patient



dissatisfaction with the health care experience (Ngo-Metzger, et al., 2007). These adverse consequences of language discordance are mutually interacting and reinforcing.

**Reduced intrinsic motivation.** Patients' psychological orientations and proclivities pertaining to intrinsic motivation, cognitive appraisal, and affective response shape patients' interactions with providers (Wagner & Bear, 2009). Language discordance can lessen the degree of a patient's intrinsic motivation to communicate with their providers (Sudore, et al., 2009). Moreover, communication discordance potentially presents a significant barrier that undermines Spanish-speaking Latinos' motivation to interact and share health care information with providers (Sudore, 2009). For instance, Rivadeneyra, Elderkin-Thompson, Silver and Waitzkin (2000) found that Spanish-speaking patients were less likely to reveal symptoms, expectations, and personal views about care to their providers than were English-speaking patients.

**Underutilization of health care.** A patient's lack of communicative proficiency in a language that is not the patient's primary language is a substantial barrier to the utilization of essential health services (Flores, 2005; Timmins, 2002). Latinos who speak Spanish at home are at higher risk for not receiving health care services than are Latinos who speak English at home (Blendon, 2007; Cheng, 2007; Dubard & Gizlice 2008). This non-receipt of recommended health care services manifests in several ways. Based on patients' reports, LEP Latinos report less access to care (Shi & Stevens); fewer health care visits to a provider (Derose et al., 2000); lower rates of insurance (Capitman, 2009) and usual sources of care (Ponce, Hays, & Cunningham, 2006). Compared with non-Latino Whites, monolingual Spanish-speaking Latinos have less access to care (Cristancho et al., 2008; Shi, Lebrun, & Tsai, 2009); and less use of health services for

which they are eligible (Cheng et al., 2007; Derose, 2000), including lower utilization of mental health services (Kouyoumdjian, Zamboanga, & Hansen, 2003).

**Limited or inaccurate patient–provider communication.** Regardless of their level of English proficiency, Latinos often report being unable to communicate effectively with health care providers due to language discordance (Timmins, 2002). In comparison with English-proficient non-Latinos, LEP Latinos report having considerably greater difficulty communicating with providers (i.e., Latino patients experience difficulty more frequently and the difficulty that they experience has greater clinical significance; Flores, 2005; Gallagher, Porter, Monuteaux, and Stack, 2013). Few studies have investigated the influence on health outcomes of providers’ attempts to communicate in languages in which the providers are not proficient (i.e., Spanish; Timmins, 2002). However, research on Latino patients shows that utilizing care provided by a language-concordant provider can improve quality of care and health care outcomes (Fernandez et al., 2007). Studies in almost all U.S. regions show that Latinos have difficulties finding a Spanish-speaking provider (Yoon, Grumbach, & Bindman, 2004).

**LEP language discordance and treatment.** For LEP patients, language discordance imposes challenges to receipt of treatment. For example, Clark and colleagues (2004) point out that language discordance imposes a considerable barrier to patients’ participation in prescribed treatment plans recommended by providers. Similarly, patients’ compliance in taking prescribed medications or patients’ adherence to provider-recommended behavioral changes (e.g., diet, exercise, smoking, stress management) may be influenced by how well the patients communicate with providers. In the case of Spanish-predominate Latinos, language discordant health care is less

efficacious than is the language concordant health care that non-Latinos whites receive (Flores, 2005). For example, Spanish-speaking Latinos receive fewer recommendations for health care services and treatments (Blendon et al., 2007; Cheng, 2007; Dubard, 2008; Levas, Dayan, Mittal, Stevenson, Bachur, Dudley, Bajaj, et al., 2014).

Furthermore, studies show providers interact less with their non-English speaking patients. For example, Spanish-speaking patients interviewed by English-speaking providers are less likely to receive recommendations regarding health issues from their providers and are more likely to have their comments ignored (Rivadeneira et al., 2000). In addition, in comparison with non-Latino Whites, Spanish-speaking Latinos receive less health care promotion information (e.g., regarding diet) from English-speaking providers (Gonzalez et al., 2009).

**Inadequate adherence to care regimens and other aspects of treatment.**

Latinos who speak Spanish at home may have lower rates of adherence to care plans than do Latinos who speak English at home (Rivadeneira, 2000). Latinos' low adherence to providers' recommended treatment recommendations and with care itself may result in less than optimal health care outcomes in this population (Timmins, 2002; Levas et al., 2014).

**Suboptimal health care outcomes.** Latinos who predominantly speak Spanish at home experience unexplained poor medical outcomes in various illnesses more frequently than do Latinos who speak English at home (Rivadeneira, 2000). In one study, Latino immigrants were found to have a greater rate of diminished survival after surgical removal of a tumor of the head of the pancreas than non-Latinos (Bathe et al., 2001).

However, no dissimilarities in the type of treatment were documented that would account for this difference in outcome (Bathe, 2001).

**Patient dissatisfaction with health care.** Morales and colleagues (1999) have found that Spanish-speaking Latinos are dissatisfied with providers' communication more often than are English-speaking Latinos and non-Latino Whites. However, when Spanish-speaking Latino patients are able to communicate with their providers in the patients' native language, better health care outcomes result—for example, these patients fewer hospital admissions (Hampers & McNulty, 2002), and greater patient satisfaction with communication (Saha, Komaromy, Koepsell, & Bindman, 1999), these outcomes are superior to Spanish speaking Latinos who communicate with their providers in English (Carrasquillo, 1999; Timmins, 2002; Wisnivesky et al., 2009).

### **Impact of Language on Reporting of GI symptoms**

Few studies have examined the impact of language discordance on how Spanish-speaking Latinos report GI symptoms. However, one study has illuminated the unique way Spanish-speaking Latinos reported symptoms of IBS. Another study, which examined how Latinos report symptoms of acute myocardial infarction (AMI), suggests that this population report symptoms of AMI that are less frequently reported than do non-Latino Whites (Meshack, 1998). Two studies have described an association between symptoms of GI symptoms, depression, and higher rates of suicidality among Latinos (Magni, et al., 1993; Magni, et al., 1998).

Barakzai and colleagues (2007) conducted a retrospective review of charts of Mexican-American patients diagnosed with IBS at two large medical centers in central California. Demographic information was collected on study participants and descriptive

statistics were used to determine how symptoms were reported. The authors discovered that only 63% of the Mexican-American patients in this study reported symptoms that met any of the diagnostic criteria used to diagnosis IBS in clinical settings (i.e., Rome II criteria). The study also found that Mexican-American patients reported symptoms unrelated to the GI system, such as dizziness (11%), myalgias (11%), and headache (14%). Additional findings included patients' descriptions of symptoms that used culturally specific symptom expressions that [in some instances] were metaphoric or idiomatic (such as "cold bones" and "cold stomach"; Barakzai et al., 2007, p. 263).

Similarly, Meshack and colleagues (1998) conducted the first comparative study to examine differences between Mexican Americans and non-Latino Whites in their reporting of symptoms of myocardial infarction (MI). The sample consisted of 589 adult Mexican Americans and non-Latino Whites. Their most frequently reported symptoms were chest pain (83%), chest pressure (67%), and sweating (64%). The authors also discovered that Mexican Americans were more likely to report symptoms of MI in terms of having "upper back pain" and "palpitations," whereas non-Latino Whites were more likely to report symptoms of MI in terms of having "chest pressure" and "jaw pain." However, there is paucity of studies examining how Latinos' culturally and linguistically unique ways of reporting symptom affect diagnosis of illness in this population (Diaz, Minsky, Miskimen, Gara, & Escobar, 2003). Moreover, the influence of language on the diagnostic patterns of GI disease as experienced by Latinos is also not well understood.

In a survey of Latinos who reported symptoms of chronic abdominal pain, Magni (1998) found that this group had higher rates of suicidal ideations and suicide attempts (up to three times more frequent) than did those without chronic abdominal pain.

### **Impact of Language on Diagnostic Patterns**

The impact of language on diagnosis of GI illness among Spanish-speaking Latino immigrants is understudied. However, studies show that for Spanish-speaking Latinos, patient–provider language discordance can lead to miscommunication and misinterpretation of symptoms (Minsky, 2003).

Rueda-Lara and colleagues (2003) have described two case studies in which Spanish-speaking patients experienced a delay in the diagnosis and treatment of pituitary adenoma tumors. The researchers found that Spanish-speaking patients with profound psychiatric symptoms experienced ineffective communication while reporting their symptoms to a provider due to language discordance. Therefore, the authors concluded that language discordance contributed to poor health care outcomes—including misdiagnosis of symptoms and delay in treatment in Spanish-speaking patients (2003). Other studies support the conclusion that patient–provider language discordance may impede or vitiate accurate diagnosis of illness (Diaz et al., 2009; Minsky et al., 2003)

Multiple studies have found that in language-discordant clinical encounters, providers diagnosed patients' symptoms as being more severe than providers did when diagnosing in non-language-discordant clinical encounters (Del Castillo, 1970; Price & Cuellar, 1981; Vega, Sribney, Miskimen, Escobar, & Aguilar-Gaxiola, 2006). Additional evidence suggests that such misdiagnosing symptoms results in erroneously high rates of certain illnesses in non-English speaking patients (Flaskerud & Liu, 1991; Lopez, 1989; Marcos, 1988; Sue, Fujino, Hu, Takeuchi, & Zane, 1991); delayed care and inappropriate treatment (Rueda-Lara, 2009).

### **Impact of Language on Health Care Outcomes**

Few studies have been conducted on the impact of language on health care outcomes of Spanish-speaking Latinos who report GI. However, one study has examined Latinos' experience of acute GI illnesses and found disparities in wait times for assessment. In this investigation, Wu and colleagues (2009) analyzed data from the National Hospital Ambulatory Medical Care Survey (NHAMCS) from 1997 to 2006. These authors sought to determine if race and ethnicity were factors in wait times experienced by patients with GI illness. The researchers discovered that Latinos experienced considerably longer wait times (i.e., intervals recommended for triage) for acute GI condition assessment (i.e., appendicitis assessment) than did non-Latino Whites. In addition, Latinos waited twice as long to be assessed for acute GI as did non-Latino Whites. Furthermore, Latinos were more likely to experience delayed clinical assessment and treatment than were non-Latino Whites. The mean wait time for Latinos to be assessed for acute appendicitis (91.2 minutes) was more than twice that for non-Latino Whites (43.5 minutes; Wu, 2009).

### **Summary of Studies on Language and Latino Health**

Language discordance in health care settings has been extensively studied. Preventing and reducing the frequency of language-discordant health care encounters and reducing miscommunication between providers and LEP Latino patients are topics frequently discussed in the literature. Evidence across studies suggests that language discordance result in Latinos' experiencing (a) decreased access to care (Moreno, 2009); (b) decreased quality of care (Baker, 1996); (c) disproportionate rates of clinical diagnoses (Diaz, 2009; Marcos, 1988); (d) misdiagnosis of symptoms (Cuellar, 1981; Del

Castillo, 1970; Minsky, 2003); (e) delayed care (Wu et al., 2009); and (f) negative health care outcomes (Bathe et al., 2001; Flaskerud & Liu, 1991; Rueda-Lara, 2003; Sherraden & Barrera, 1996; Wisnivesky et al., 2009). Although studies conducted on language and Latino health and health care have several strengths, these studies also have limitations in the validity of their findings. The following discussion reviews the strengths and weaknesses of leading studies on language and Latino health and health care.

Strengths of the studies on language and Latino health include the examination of a diverse and understudied population (Ponce et al., 2006); accumulation of valuable qualitative data (Sherraden & Barrera, 1996); determination of current national prevalence estimates for usual source of health care (Gonzalez et al., 2009); and supplementation of the literature on reporting and diagnosis of symptoms (Minsky, 2003).

Weaknesses in Latino language-discordance literature include recall bias and lack of assessment of participants' self-reported English language proficiency (Baker, 1996; Cheng et al., 2007; Gonzalez et al., 2009); high attrition rates (Derose & Baker, 2000); lack of assessment of acculturation and health literacy and lack of determination of nationality (Diaz, 2009; Marcos, 1988; Minsky, 2003); and limitations in study designs that precluded analyses of cause-and-effect relationships (Moreno, 2009; Sherraden & Barrera, 1996). The generalizability of some studies was constrained by limitations in sample size and diversity, setting diversity, and geographic scope (Barakzai et al., 2007; Diaz, 2009; Enuidanos & Rosen, 1997; Meshack et al., 1998). In addition, the variety of methods and designs used in these studies inhibits cross-study comparison and multi-study analyses. For example, designs have included meta-analysis (Dubard et al., 2008;



Marcos, 1988; Meshack, 1998; Minsky, 2003; Morales, 1999), cross-sectional analysis (Cheng, 2007; Ponce, Hays, & Cunningham, 2006), exploratory ethnography (Sherraden & Barrera, 1996), qualitative interviews (Derose & Baker, 2000), cross-sectional study (Morales, 1999), cross-sectional, stratified, randomized telephone interviews (Gonzalez et al., 2009), case studies (Rueda-Lara, 2003), multistage cluster design (Vega et al., 2006), structured interviews (Diaz, 2009), and retrospective chart review (Barakzai et al., 2007).

Moreno and colleagues (2009) have conducted a cross-sectional survey to examine data from 1,590 LEP Latino adults. The authors sought to identify and examine associations between interpreter use and LEP Latinos receipt of advice from providers regarding their newly prescribed medication(s). The strengths of this investigation included having a large sample size, making a landmark contribution toward clinical understanding of the impact of language on health care disparities, and including participants from multiple sites across the U.S. Weaknesses of the Moreno et al. study included non-inclusion of Latinos who were not Spanish-language predominant; a preponderance of female participants; and a preponderance of participants who had insurance coverage. Accordingly, the sample was not representative of Latinos nationwide, which further limited the generalizability of the study's findings. Finally, the study's cross-sectional design did not allow examination of cause-and-effect relationships between interpreter use and receipt of medication.

Meshack and colleagues (1998) conducted a study to identify and compare differences in the reporting of symptoms of acute myocardial infarction (AMI) by Mexican Americans and by non-Latino Whites. The strengths of this study included the

large sample size ( $N = 589$ ), and its discovery of evidence that differences exist between Mexican Americans' patterns of reporting AMI and those of non-Latino Whites. As with studies examined earlier in this literature review, the Meshack et al. study had weaknesses that reduced generalizability. For example, the study did not examine how language and language discordance influence the presenting and reporting of symptoms by Latinos; in this regard, earlier studies have shown that language may impact the reporting of symptoms (e.g., atypical symptoms), and the clinical diagnosis of symptoms (e.g., misdiagnosis; Diaz et al., 2009; Marcos, 1988). Other weaknesses of the study were its sample being restricted to Mexican Americans who resided in Texas and who had symptoms of AMI. Therefore, the study could not be generalized to other Latino groups (e.g., Colombian groups or Guatemalan groups) or settings (Meshack, 1998).

Wu and colleagues (2009) analyzed data from the National Hospital Ambulatory Medical Care Survey (NHAMCS), previously collected from 1997 to 2006, inclusive. The authors sought to report wait times for visits to U.S. emergency departments (EDs) for acute gastrointestinal illnesses. The strengths of this study include; (a) the investigation's analysis of rigorously obtained NHAMCS data; (b) the fact that the NHAMCS data were geographically diverse in origin from emergency and outpatient departments across the U.S.; the broad geographical scope of this data enabled nationwide assessment of which racial and ethnic ED wait times for patients diagnosed with acute gastrointestinal illnesses; (c) identification of important health care disparity data in wait times and delays in physician assessment for Latino patients with acute gastrointestinal illnesses. Despite the strengths of the study, several limitations reduced the validity of the study's findings. For example, wait-time data were missing for about

10% of the NHAMCS survey years included in the study sample. In addition, researchers were not able to assess the role of socioeconomic factors or how the volume of patients in the emergency department (ED) may have contributed to the findings of observed racial and ethnic differences in ED wait times.

### **Interpreters—A Key Strategy to Address Language Discordance**

A substantial body literature examined strategies to address the problem of language discordance in health care settings (Cheng, 2007; Flores, 2005; Morales, 1999). One leading strategy in this regard is the use of interpreters. The following sections review studies on the epidemiologic and clinical perspectives of the use of professional interpreters and ad hoc interpreters in clinical settings. These studies also discuss benefits and drawbacks of professional interpreters use.

#### **Professional Interpretation**

The importance of using a well-trained professional interpreter to communicate with non-English speaking patients has been well established in literature (Bischoff & Hudelson, 2009; Flores, 2005). Evidence indicates that well-trained professional interpreters (a) reduce language discordance (Arunguri, Davidson, & Ramirez, 2005); (b) improve compliance with medication regimens (Jacobs, 2001); (c) increase preventive care (Jacobs, 2001); (d) minimize delays in care (Fernandez, 2005); and (e) improve health care outcomes among Latinos (Hampers & McNulty, 2002; Timmins, 2002).

Conversely, evidence suggests the use of poorly trained interpreters (e.g., “ad hoc” interpreters) results in higher rates of miscommunication, misinterpretation of health care information, and poor health care outcome for Latinos (Elderkin et al., 2001).

**Benefits of professional interpreter use.** Studies suggest that NES patients benefit from the use of professional interpreters. Reported benefits include increased delivery of preventive care—for example, use of fecal occult blood tests (Jacobs, 1999; Ponce, 2006) and reduced delays in care (Fernandez, 2005). When professional interpreters are used consistently, fewer language discordance-related problems arise (Enuidanos & Rosen, 1997; Ramirez, 2009). However no studies have investigated possible mechanisms by which interpreters may affect Latinos' reporting of GI symptoms.

Although a significant body of literature supports the use of professional interpreters, dissenting studies have cited significant drawbacks in the use of professional interpreters (Elderkin-Thompson, 2001; Rivadenerya, 2000). Moreover, the reported impact of the use of professional interpreters seems to depend on the study methodology and sample selection. Therefore, follow-up studies that use more rigorous approaches (i.e. randomized clinical trials) should be conducted to better understand how the intervention (e.g., use of professional interpreters, use of bilingual providers) impacts care provided to Latinos.

**Drawbacks of professional interpreters use.** Some unfavorable results have been reported with the use of professional interpreters, including miscommunication and misinterpretation of health care information (Rueda-Lara, 2003); diminished direct patient–provider communication (Rivadenerya, 2000); and longer wait times (Garrett, 2008).

## **Ad Hoc Interpretation**

Baker (1996) and Lee et al. (2006) have noted that, in lieu of professional interpreters, providers frequently use ad hoc interpreters—that is, friends and other non-professional interpreters. However, the majority of studies does not support provider use of ad-hoc interpretation except in cases of emergency (Timmins, 2002). The following sections discuss the benefits and drawbacks of ad hoc interpretation.

**Benefits of ad hoc interpretation.** A limited number of studies suggest that patients and their families prefer the use of ad hoc interpretation in lieu of use of a professional interpreter (Free, Green, & Bhavnani, 2002). Other researchers found that providers, too, may benefit from the use of ad hoc interpretation in situations of time constraint (Lee, 2006; Ramirez, 2008). However, as with the use of professional interpretation, several studies cite drawbacks associated with the use of ad hoc interpretation (Lee et al., 2002).

**Drawbacks of ad hoc interpretation.** Studies show that the use of ad hoc interpreters can lead to inaccurate communication miscommunication and misinterpretation of health care information (Flores, 2003). In one study, Elderkin-Thompson (2001) discovered that when interpretation was conducted by bilingual nurses—in lieu of interpretation by professional interpreters—clinically significant miscommunication (e.g., omission of medical history in patients' medical charts) occurred. However, the characteristics of professional interpreter use by providers are not well documented.

**Provider's use of professional interpreters.** Researchers have found that when providers are faced with instances of patients-provider language discordance, the

providers often turn to ad hoc interpreters to facilitate communication with NES patients. Lee and colleagues (2006) conducted national survey to determine providers' use of professional interpreters. These researchers found that when providers were faced with language barriers, 77% of medical residents reported they used interpreters "sometimes," and 84% claimed they used ad hoc interpretations (including patients' family members, p.2). Similarly, other studies have discovered that providers' use of professional interpreters is infrequent (Baker, 1996)—especially in the emergency room (Garrett, 2008).

### **Summary of Studies on Strategy to Address Language Discordance**

The importance of using well-trained professional interpreters to improve communication between providers and their LEP and NES patients is well established in the literature (Bischoff & Hudelson, 2009). Although studies conducted on interpreter use have had several strengths, in the case of each study, design weaknesses have limited the study's validity. For example, in one study interpretation was mostly conducted by hospital staff whose language proficiency had not been assessed (Baker, 1996).

The studies on interpreter use have several strengths: large sample size (Gonzalez et al., 2009; Hampers & McNulty, 2002); control of confounding variables (Lee et al., 2002); contribution to the body of knowledge regarding providers' use of ad hoc interpreters (Free, Green, Bhavnani, & Newman, 2002); elicitation of patients' perspectives (Free et al., 2002); and assessment of the various interpretation methods (Lee, 2002).

On the other hand, as Flores (2005) has pointed out, the research on interpreter use and services also has several methodological problems. One study's design, for

example, involved a substantial diversity of interpreter types (e.g., bilingual providers, professional interpreters, ad hoc interpreters), but the effect of each interpreter type on outcomes of the study was not examined (Baker, 1996). Another study's validity was limited by researchers' not rating patients' self-reported English language proficiency, by failure to rate providers' Spanish language proficiency, and by failure to examine effects of language discordance on diagnosis accuracy (Baker, 1996). Finally, a study by Jacobs (1999) did not take into account the type of patient visit (e.g., complete physical, emergent care)—an oversight that conceivably affected the study's outcome. The following discussion reviews the strengths and weakness of leading studies on interpreter use.

Hampers and McNulty (2002) conducted a cohort study to examine language discordance and providers' use of interpreters in communications with non-English-speaking parents of children brought into the emergency room. The study had several strengths, such as a large sample size ( $N = 4,146$ ) and stratification of the results according to interpreter and bilingual provider. Although the study had several strengths, several weaknesses in the study limited the study's findings. For example, some providers spoke Spanish as a first language—a factor that can affect how providers make health care decisions when caring for Spanish-speaking patients and that can consequently influence a study's outcome. Furthermore, the researchers did not assess participants' English language proficiency or ethnicity, additional weaknesses in the study. Also, the study lacked an appropriate comparison group (Flores, 2005): researchers compared patients who used ad hoc interpreters with patients who did not use

interpreters—another design limitation that could have affected the study's outcome (Hampers & McNulty, 2002).

Free and colleagues (2002) conducted a qualitative study that examined young people's perspectives with regard to their translating for family members due to interpreter service staffing deficiencies. This study's strengths included the use of a purposive sample that selected young people who were willing to impart their knowledge, perspectives, and experiences with interpretation (Tongco, 2007). In addition, by contributing to the body of knowledge regarding providers' use of ad hoc interpreters, this study supplanted a previous gap in clinical understanding. However, the study had several limitations. For example, the purposive sample did not include children younger than nine years of age. In this regard, such young subjects might have had developmentally based perspectives different from those of the participants actually included in the study; the study's exclusion of young subject decreased the study's applicability. Finally, the study was conducted in London and may not reflect the perspectives of the immigrant population in the U.S. or, more specifically, in California.

Baker and colleagues (1996) conducted a cross-sectional study that investigated how often providers used interpreters when caring for Spanish-speaking patients. The study had several strengths, including the assessment of patients' health literacy. The study's findings pointed to the importance role of oral patient-provider communication when engaging with Spanish-speaking Latinos who have low health literacy. In addition, in order to reduce selection bias, researchers enrolled patients eligible for the study consecutively in the order of their arriving at the clinic. Although the study had several strengths, the study also had several design weaknesses. First, the sample mostly



consisted of women participants who presented in a non-urgent-care area of the emergency department between the hours of 7:00 a.m. and 11:00 p.m.—factors that decreased the generalizability of the study to other settings and populations. Second, the investigation did not rate participants' self-reported English language proficiency and providers' Spanish-language proficiency. Third, the study did not provide information on the type of interpreters used and their levels of competence (i.e., whether the interpreters were trained, professional, language-proficient providers); it has been observed that the type of interpreter employed can impact study outcomes (Flores, 2005).

Garrett and colleagues (2008) conducted a multilingual telephone survey and medical record reviews to assess modes of communication. These authors sought to investigate the level of health care complexity encountered by LEP Latino patients and the probability of providers' use of professional interpreters. The sample consisted of 258 LEP Latino patients. The study's findings corroborated previous research findings regarding providers' infrequent use of professional interpreters. For example, the authors discovered that 69% of LEP Latino patients cared for did not have a professional interpreter. Although the Garrett et al. study had strengths, the study also had several limitations. For example, the study used a telephone survey, an information-gathering approach that excluded individuals who did not have telephones; it is possible that telephone owners might differ from non-telephone owners in ways of responding to surveys. Also, the study did not determine providers' frequency of interpreter use nor how providers' patterns of interpreter use affects health care delivery and outcomes. Finally, the study's sample size was small; the sample itself consisted of a convenience sample of patients from one hospital in Australia. These limitations reduced the

generalizability of the study's findings to other ethnic groups and to other settings (Garrett, 2008).

The literature on interpreter service use has additional limitations. For example, some studies have not provided information on the quality and type of interpreters used (i.e., whether the interpreters were trained, professional, language-proficient providers). Other studies have lacked appropriate comparison groups (Flores, 2005). For example, one study's sample included both patients who used ad hoc interpreters and patients who did not use interpreters—another design inconsistency that could affect outcome (Hampers & McNulty, 2002). Other studies were limited by the inconsistent use of methodologies. These studies have used, for example, cross-sectional surveys (Baker et al., 1996; Moreno, 2009); qualitative, in-depth, semi-structure interviews (Free, Green, & Bhavnani 2002); self-administered, post-visit questionnaires (Lee et al., 2002); qualitative, cross-sectional design (Elderkin-Thompson, 2001); and a communication study with post-visit interviews (Aranguri, Davidson, & Ramirez, 2005). Moreover, the variety of the studies' sample selection criteria along with the variety of methodologies, have limited the generalizability of these studies to other populations. Finally, several deficiencies in the published literature investigating the impact of interpreter use when caring for Latinos suggest areas in particular need of further investigation (Flores, 2005).

#### **Areas in need of further investigation**

The impact of various types of interpretation on improving clinical communication and health care outcomes for Latinos needs further investigation. Furthermore, studies should also be conducted to compare the relative effectiveness of bilingual providers, professional interpreters, and ad hoc interpreters on health care

delivery and outcomes of LEP and NES patients. Additional studies examining the impact of culture on Latinos' use of interpreters are required in order to increase providers' understanding of the potential mediating role of culture on this population's decisions to use interpreter services (Flores, 2005). Several studies have found that clinically significant misinterpretations of health care information result from use of professional interpreters (Flores et al., 2003); therefore, studies are needed to better understand the impacts of interpreter training programs in reduction of misinterpretations by interpreters (Flores, 2005; Timmins, 2002). Furthermore, studies that have examined consequences (e.g., misdiagnosis) associated with communicating with Latinos without a professional interpreter have not used rigorous methods (e.g., randomized, controlled trial) for studying interventions (Flores, 2005). To rectify this research deficit, randomized, controlled trials should be performed to compare the effectiveness, impact on health care outcomes, and costs of various types of interpreter services (Flores, 2005, Timmins, 2002). Finally, studies on the use of professional interpreters have not presented cost-benefit analyses, which are often required before implementation of interventions (i.e., use of well-trained professional interpreters (Flores, 2005).

Studies of the drawbacks of ad hoc interpretation have been limited by (a) small sample sizes, (b) samples consisting mostly of Spanish-predominate Latinos (c) professional interpreters having limited or no training, and (d) encounters that used nurse interpreters as translators (Elderkin-Thompson, 2001; Flores, 2003). Therefore, studies with larger sample sizes and appropriate comparison groups are warranted. Finally, studies investigating interpreter use have not examined how patients' cultural values, attitudes, and health practices influence their decisions to use interpreter services (Flores,

2005). For example, if offered the service of a male interpreter, a female Latina patient may insist on the use of an untrained female family member; this use of untrained interpreters can have deleterious consequences (e.g., misdiagnosis, delayed care) for this population (Flores, 2005).

### **Discussion**

A large body of literature has discussed language discordance in health care settings. Studies support the conclusion that, in contexts of language discordance, Latinos' inability to effectively communicate with providers is detrimental to patient health and health care outcomes (Flores, 2006; Jacobs, 2004). This literature review indicates that health care providers need to gain better understanding of how language discordance affects Latinos reporting of illness (Dubard, 2008). For Latino immigrants, the ability to communicate and describe symptoms of illness is essential for safe and correct assessment, diagnosis, and treatment (Diaz, 2009; Flores, 2006).

Researchers suggest that Latinos' demographics are pertinent to their health care disparities (Capitman, 2009). However, the extent to which undocumented, Spanish-speaking Latinos suffer higher rates of health care disparities needs to be explored more thoroughly. Moreover, knowledge of how social and cultural factors—such as language discordance—contribute to health care disparities is inadequate. Other gaps in literature include the lack of studies examining the influence of language on the diagnostic strategies of providers caring for Latinos immigrants (Zayas, Torres, & Cabassa, 2008). Moreover, the literature does not present data regarding the direct impact of language discordance on health care outcomes of GI illness in this population. The majority of studies conducted on this population are descriptive in nature (Timmins, 2002).

Some studies suggest that Latinos may use metaphors when describing some illnesses (Barakzai et al., 2007; Dobkin, de Rios, & Achauer, 1990). However, there are gaps in the literature regarding Latinos' use of common modes of expression to report GI symptoms. This literature review was not able to find studies that have examined the perspective of Spanish-speaking Latinos who report GI symptoms in clinical contexts of language discordance. The literature describes great diversity in the health of the Latino population—a fact that makes it difficult to describe this population's health status (Lara, 2005). Studies suggest that Spanish-speaking Latinos suffer from higher rates of health disparities than do their English speaking counterparts (Cheng, 2007). In addition, Spanish speaking Latinos report having poorer health status when compared to English speaking Latino (Franzini & Fernandez-Esquer, 2004). However, the findings of studies that examine Latino health are ambiguous and in some cases even contradictory (Lara, 2005; Franzini, Ribble, & Keddie, 2001). Extant research concludes that Latinos' health status highly correlates with their level of acculturation (Gallo, 2008). At the same time, we note that health scientists and providers have thus far not articulated a comprehensive conceptual framework of what “good health” entails for the Latino population. A concept analysis was not found on the terms *health* and *poor health status* as these terms are used by Latino patients; analysis of Latinos' usage of these terms would contribute to understanding of these phenomena.

The literature reveals that Spanish-speaking Latinos have higher rates of health care disparities (e.g., lower rates of usual source of health care) than do non-Latino Whites (Gonzalez, 2009). Gaps in the literature include a deficit of studies comparing differences in health care disparities experienced by Latino subgroups (e. g.,

undocumented individuals). The few studies that have compared health care disparities of Spanish-speaking, undocumented Latino immigrants with those of documented English-speaking Latinos suggest there are significant differences in health care access between the groups (Morales, 1999).

The prevalence of GI illness among Latino immigrants is not well documented. However, one study has found a recent rise in the prevalence of GI illness among Latinos (i.e., gastroesophageal reflux disease [GERD], Yuen, et al., 2010; and inflammatory bowel disease, Hou, El-Serag, & Thirumurthi, 2009). However, few studies have reported on Latinos' health care disparities related to GI illness. However, these studies do suggest that Latinos suffer more frequently from more advanced stages of GI illness (e.g., hepatitis; Blessman, 2007) and experience higher morbidity than do non-Latino Whites (Blessman, 2007). The literature has not closely examined the causes of Latinos' more advanced GI illnesses and worse health outcomes. Researchers have hypothesized that language and culture play a role in the health and health care of Latinos. For example, cultural beliefs about the causes and treatments of illness may create barriers in health-seeking behaviors, and it is possible that these barriers may lead to delayed care and treatment of Latino patients (Calvillo & Flaskerud, 1991).

Studies show that Latinos have limited access to care when compared to non-Latino whites (Flores, 2006). For example, documentation exist to suggest that Latinos experiences longer wait times in the ER when compared to non-Latino whites (James, Bourgeois, & Michael W. Shannon, 2004 ). However, only one Latino health study has documented longer wait times prior to receipt of primary clinical assessment for acute GI symptoms. (In this study, the researchers did not ascertain whether the longer wait times

were related to language discordance (Wu, 2009). Latino health studies would have benefited from knowledge of whether factors such as Latinos' cultural values or language impacted how Latinos reported their initial GI symptoms to the provider in the emergency room. Other gaps in the literature include an absence of studies regarding the significance of language and language discordance for the diagnosis of GI illness in the Latino population (Barakzai et al., 2007). Furthermore, discrepancies exist in the Latino health literature investigating possible association between Latinos' reporting GI illnesses in clinical situations of language discordance and negative health care outcomes (e.g., misdiagnosis, delayed care). One study, however, has found a clinically significant delay in care for acute GI conditions among Latinos (Wu, 2009).

The review of literature suggests that culture affects Latinos' engagement in treatment and care (Wisnivesky, 2009). However, existing studies on Latino culture and engagement in treatment and care have examined culture as a barrier to care when Latino patients' culture is different from their providers' culture. For example, researchers often describe Latino culture as a barrier — (rather than as a component of cultural discordance). Moreover, several authors found that culture can undermine quality of care (Flores, 2003, Rueda-Lara, 2003 Weisman, et al., 2000). As Juarez, et al., (1998) and Minsky (2003) have discussed, the literature has not clearly explained how culture impacts communication between providers and Latino patients. Therefore, more studies are needed to examine more precisely how normative cultural values shared by most Latinos directly impact communication with providers. Moreover, qualitative studies could provide valuable data regarding the perspectives of Latinos regarding which cultural values they believe have the greatest impacts on their ability to effectively

communicate with providers. In addition, studies show that Latino patients' degrees of acculturation affect this population's health care utilization (Lara, 2005). However, due to the complexity of the acculturation process, investigators have not identified the best means of assessing possible risk factors (e.g., health care beliefs) believed to be associated with an individual's level of acculturation. In addition, one study found that legal status is a significant factor that affects health care for this population (Rehm, 2003). However, studies that report the legal status of Latino participants are deficient.

Studies have shown that health care for Latinos is influenced by their language proficiency in English as well as by their level of health literacy (Baker, 1998). Moreover, language discordance can lessen the degree of a patient's intrinsic motivation to communicate with providers (Sudore, 2009). Studies that directly examine the impact of language discordance on the reporting of GI symptoms are limited. Only one retrospective study—a study on IBS—has directly examined the reporting of GI illness. This study illuminated the culturally specific, sometimes idiomatic ways in which Latinos sometimes report IBS (Barakzai et al., 2007). Although other studies have examined Latinos' reporting of symptoms of myocardial infarction (Meshack, 1998) and of abdominal pain (Magini, 1998; Magni, 1992), these studies make no mention of language discordance. Given the dearth of research investigating the impact of language discordance on Latino immigrants' reporting of GI illness symptoms, more studies are warranted.

A few studies have examined miscommunications and misinterpretations of symptoms by providers in contexts of language discordance. These studies were found in the discipline of psychiatry (Rueda-Lara, 2003); accordingly, these findings are difficult



to generalize to other populations (Del Castillo, 1970; Diaz, 2009; Flaskerud, 2000). In several studies, researchers found when language discordance exist between the providers and Latino patient that providers have incorrectly reported higher rates of certain illnesses (e.g., psychosis; Flaskerud & Liu, 1991; Lopez, 1989; Marcos, 1988; Sue, Fujino, Takeuchi, & Zane, 1991).

Studies suggest that Latinos' reporting of symptoms is influenced by cultural beliefs (Minsky, 2009), and, moreover, that reporting symptoms in an atypical way (Barakzai et al., 2007), can lead to misdiagnosis or delay in diagnosis of symptoms by providers (Diaz, 2009). However, the data reported in the literature have been insufficient to enable norms to be established regarding reported symptoms of Spanish-speaking Latino immigrants.

Studies that thoroughly investigate presentation and reporting of symptoms in clinical situations of language discordance involving Latinos are mostly found in the discipline of psychiatry (Rueda-Lara, 2003). However, research also suggests that Spanish-speaking and LEP Latinos are at higher risk for misdiagnosis of symptoms than are English-proficient Latinos and non-Latino Whites (Diaz, 2009; Minsky, 2003). Some studies propose that Latinos' normal presentation or reporting of symptoms differs from that of non-Latino Whites, and that this difference contributes to providers' misinterpretation of symptoms (Barakzai et al., 2007; Diaz, 2009; Vega, 2006).

Researchers found that English speaking providers attempt to communicate with non-English speaking Latinos patients. For example, one study has discovered that up to 59% of house staff reported they did not speak Spanish, and 53% of the house staff reported making attempts to communicate with Latino patients despite having inadequate

Spanish proficiency (Burbano, 2003). How a provider's proficiency in a second language impacts care provided to Latinos has not been explored in depth (Diamond, 2009).

Studies suggest that the best way to improve communication with Spanish-speaking Latinos is to use well-trained professional interpreters (Flores, 2000; Ramirez, 2009). Most literature on the subject favors the use of professional interpreters over the use of ad hoc interpreters. However, several studies have found adverse consequences (e.g., miscommunication of health care information) when professional interpreters were used (Bernard, 2005; Garrett, 2008). Data regarding patterns of use of professional interpreters by providers in the Latino patients were not discovered in this review of literature.

### **Conclusion**

To improve the assessment, diagnosis and treatment of symptoms additional knowledge regarding how this population presents and reports symptoms of GI illness is vital (Diaz, 2009; Minsky, 2003; Rueda-Lara, 2003). Currently, data do not clearly identify language discordance as a primary factor influencing the presentation, reporting, and diagnosis of illness experienced by Spanish-speaking Latino immigrants.

Limited studies have found that Latinos suffer more frequently from poorer health care outcomes associated with GI illness than do non-Latino Whites (Blessman, 2007). Studying the lived experience of Latinos with GI illness symptoms could lead to important knowledge about these issues. Valuable insight into the barriers and aids to communication of symptoms and concerns can be elicited from patients regarding what might improve medical encounters. Accordingly, my study sought to understand

1. how, from the patient's perspective, receipt of health care for GI illness

management proceeds in situations of language discordance;

2. how, from the patient's perspective, barriers to and aids for communicating illness concerns manifests in situations of language and cultural discordance;
3. how patients cope with communication barriers in managing GI illness; and
4. how Latinos report GI symptoms in the presence of language discordance.

## Methodology

The study utilized an interpretive narrative design to describe and interpret the perceptions of NES/LEP Latinos who report abdominal pain in language-discordant clinical encounters (Benner, 1994). *Interpretive narrative analysis* is a phenomenological research method used to explain a particular situation (phenomenon) from the perspective of the individual who is in the midst of experiencing it (Van Manen, 1990). In addition, the method aims to explain the person in the situation, at the same time considering the person's previous experiences and specific concerns. Understanding these previous experiences and specific concerns enables investigators to provide an accurate interpretation of the person's actions (Chesla, personal communication; Leonard, 1994, p. 51).

In the development of this study, I reflected on what constitutes the nature of lived experience for NES/LEP Latinos who encountered communication barriers when reporting abdominal pain to non-Spanish-speaking providers. For the participants, interpretive narrative analysis enabled collection of rich and detailed descriptions of their experiences in health care. These descriptions can be used to enhance the Symptoms Management Model and clinical understanding. Narrative analysis allowed me to investigate Latinos' everyday health and health care experiences. For example, Latinos often report not being able to express their illness concerns to non-Spanish-speaking providers (Flores, 2000, 2005). Narratives illuminated for me as an investigator the everyday life experiences of the participant while at the same time taking into consideration their "possibilities" and constraints" (Leonard, 1994, p. 47).

Interpretive narrative analysis enabled me to be situated as an engaged listener to the participant's story. Data collection and analysis proceeded concurrently with and continuously

throughout the narrative process. In addition, I as a researcher served a third role—as an interpreter who contributed to the creation of narrative data. Moreover, implementation of the study in the participant’s natural setting allowed social and physical context both to be observed and to influence participant discourse (Benner & Wrubel, 1989; Benner, 1994).

The philosophical commitment to *thrownness* is what Heidegger refers to as “always already situated-in-the-world” (Leonard, 1994, p. 47). Thrownness highlights the contextual conditions that have “shaped the informants’ lives”—for example, Latino immigrants’ experiences of migration into a western society and engagement in U.S. health care systems. These factors are frequently important in structuring the informants’ responses to situations experienced in the health care environment, and thus this research needed an approach that honors that “thrownness” (Leonard, 1994, p.47; Rehm, 2003). Thus interpretive narrative analysis is a method that has a commitment to having the voice of the participant heard (Benner & Wrubel, 1989). Therefore, interpretive narrative analysis was the best available method for the study, which had as its central objective the discovery of the lived experiences of NES/LEP Latinos’ reporting of abdominal pain in language-discordant clinical contexts.

### **Setting and Sample**

The study sample was purposive and both adult male and female Latinos were recruited for study participation. The sample size was 13. *Inclusion criteria* were that participants be (a) 18 years of age or older; (b) self-identified as a first generation, foreign-born, Latino or Hispanic immigrant; (c) a monolingual Spanish speaker or demonstrate limited English proficiency; (d) experience symptoms of abdominal pain for at least one month (e.g., irritable bowel syndrome [IBS], gastroesophageal reflux disease [GERD], gastritis, chronic abdominal pain); and (e) had self-reported to a provider abdominal pain symptoms prior to study enrollment. *Exclusion*

*Criteria:* Participants were considered ineligible for this study when (a) they were unable to participate in an interview that used an open-ended format or (b) suffered from serious mental illness that would prevent them from reflecting on their health care conditions.

### **Data Collection**

Interpretive narrative investigation utilizes interviews to gather data about participants' experiences. In the study, open-ended interviews were used to generate narrative descriptions of NES/LEP Latinos' language-discordant health care encounters in which these study participants described symptoms of abdominal pain and explain their concerns and perspectives regarding their language-discordant encounters (Caufield, 2006). The study included reflective and narrative interviews (Benner, 1994b). These interviews used open ended questions to encourage participants to discuss their experiences. Interview dialogues focused on participants' experiences in seeking care for abdominal pain and enabled participants to give direct, concrete, recent accounts of their experiences with language discordant health encounters.

Narrative questions in the interview were used to elicit the voice of the informant enabling them to describe their perceptions of everyday situations and the consequences of these situations and also to describe their resulting actions (Benner, 1994). Interviewing participants provided an opportunity for the investigator to asked questions and probes to clarify and expand upon what was being expressed by the participants (Cohen, Kahn, & Steeves, 2000). This data collection approach entailed my spending a considerable amount of time with the population in the field in order to build rapport with participants (Creswell, 2007).

Reflexive questions in interviews were used to ask participants about their abdominal pain. These interviews inquired about participants' history of abdominal pain, how the pain fit into their overall health assessment, and how their pain had been treated in the past (both in

Mexico and the United States). During the first interview, participants were asked to complete a demographic form to gain their overall perceptions of the health care system in the United States and a brief history of their immigration.

### **Study Procedures**

**Recruitment.** Upon receiving CHR IRB approval from UCSF, information describing the study was posted in designated areas of the Catholic Church in Fresno, Ca. This site was appropriate because the Spanish congregation are predominately NES/LEP Latino immigrants from Mexico. In addition, the Priest informed the researcher that he was aware of Latino immigrants in his congregation who were experiencing language barriers when seeking health care. The flyers had tear-off tabs with the investigator's contact information (Appendix D). There were no responses to the initial posting of fliers. Next, I requested guidance from the Catholic nuns who immediately contacted their Priest by phone. The Priest informed me that a Nun would arrange for me to be provided a trusted church liaison who could introduce me to participants and assist with entrée. However, potential participants continued to be reluctant to call an unknown researcher. Therefore, the Priest announced the study during Spanish mass, reiterating to potential participants where to find the study flyers. Substantial fear of being deported appeared to continue to influence potential participants, who would not take flyers from the church lobby. I then participated in two large social events at the Catholic Church, alongside the liaison in order to build rapport with the community. The liaison communicated to the congregation where to find flyers, and some potential participants took several flyers from the church lobby. The persons wanting to participate in the study phoned the investigator. Snowball sampling—in which one participant referred another patient to the study—was used with good results for the remainder of the study.

A screening phone call was conducted to be certain potential participants met study criteria. Eligible participants who chose to participate in the study were asked to negotiate (with the investigator) a mutually acceptable meeting place. At the start of the first interview, informed consent was obtained verbally in via face-to-face discussion between participants, investigator, and bilingual Spanish speaking Liaison (see Appendix C, informed Consent).

### **Data Collection**

All participants chose to have their interviews conducted in their homes. The researcher explained the purpose of the study and encouraged participants to answer questions as fully as possible, emphasizing that there are no wrong or right answers. Participants were asked to complete a demographic information form with assistance from the investigator (see Appendix B).

Data collection was accomplished through two in-depth, face-to-face interviews lasting about 2 hours each; the interviews used open ended questions. During these interviews, participants were encouraged to discuss their experiences in full (see Appendix A, Interview Guide). The initial interview took approximately 2 hours to complete. This interview focused on participants' overall experiences in seeking care for GI pain. A brief medical history of their experience with abdominal pain and its treatment were obtained. In addition, participants were asked to provide specific narrative descriptions of their experiences in seeking recent care for abdominal pain. All the participants completed a follow-up interview that also lasted approximately 2 hours to obtain additional health narratives and to check on interpretations of their stories. The total time required of participants was approximately 4 hours over the course of 6 months.



During the course of the interview, other questions and probes were used to clarify and expand content presented by the participants. During interviews, the researcher ensured that the environment was informal and comfortable and emphasized that all perspectives are respected. Participants were encouraged to verbalize their concerns. When problems occurred during the interview, an appropriate problem-resolution procedure was initiated.

Participants' responses were monitored throughout the interview. When a line of questioning appeared to make a participant uncomfortable, the participant was reminded that she or he did not need to answer every question and that she or he could terminate the interview at any time. When the participant continued to be upset, the interviewer gently guided the questions to a different topic. Commencing with recruitment, all staff assisting with this project assured potential and actual participants that their participation will have no influence on the participants' subsequent care.

### **Protection of Human Subjects**

A total of 26 interviews were first conducted in Spanish and then audio-recorded and transcribed verbatim into Spanish. After the initial transcription, interviews were translated into English. Translation into English was done by a bilingual transcriptionist under my supervision.

**Confidentiality and privacy.** All participants chose to be interviewed in their homes, ensuring privacy. During interviews, the interviewer assured participants that no identifying information would be discussed or communicated outside of the interview. Participants were reminded that their involvement was voluntary. Extreme care was taken to mask the identity of all participants in this study. In addition, data were protected from disclosure in the health care settings in which participants receive care. I accessed information via face-to-face audio taped interviews. Pseudonyms were substituted for the names of participants in transcribed texts.

Reports on participant's comments were collected into anonymous or grouped data so that no particular patient's comments could be identified.

*Rights and welfare.* All information was collected directly from participants. Participants' rights and welfare were protected by efforts to ensure that the study staff was culturally competent and also competent in approaching low-income participants with respect. I have worked closely with vulnerable populations, including Latinos, in the Central Valley for approximately 25 years. I am a Spanish-speaking registered nurse and nurse practitioner who has conducted research with this population in the past. Payment of \$10 at the completion of each interview was a small token of thanks and was not thought to be large enough to be coercive.

### **Data Management**

Interview notes and other forms of data were kept confidential and were coded for anonymity; in addition, during analysis, interview data was not shared with anyone other than the research team and the supervising faculty. All information was collected directly from the participants and filed as de-identified data in the participants' file.

### **Data Analysis**

The analysis began with data collection including written field notes from interviews and observation (Cohen et al., 2000); during data analysis, text interpretation began (Birks, Chapman & Francis, K., 2007). Data analysis is an iterative process aimed at gaining deeper understanding and ascertaining the meaning of various parts of the text; such meanings were derived from themes that emerged from interviews (Benner, 1994). Text was read thoroughly, and notes were written on page margins to form initial codes. Narratives were read several times to gain a clear understanding of the text and the context (Emami, Benner, Ekman, 2000). This approach catalyzed new understandings through the development and greater understanding of the

phenomenon being studied. Narratives allowed participants to provide an active representation of themselves and of their experiences with language-discordant clinical encounters (Benner, 1994).

Interpretive analysis refers to the three key processes: thematic analyses and narrative analysis which can result in the identification of exemplars and paradigm cases (Benner, 1985; Chesla, 1994). In thematic analysis, the researchers moved back and forth from whole texts to parts of text in search of latent textual meanings (Leonard, 1994, p. 59). This iterative data analysis process enhanced the researcher's understanding (i.e., "knowing") in the process of data analysis (Leonard, 1994, p. 59). Narrative analysis is concerned with understanding specific incidents that cause "breakdowns" (Leonard, 1994, p. 60) in participant's lives and how they coped. Moreover, a central objective of this analytical method is to enhance the investigator's understanding of the range of approaches by which problems or incidents can be considered, comprehended, and addressed (Leonard, 1994, p. 60). In addition, thoughtful re-reading of text by the researcher sought to discover "contradictions, awkwardness, and unclear language in the participants' discourse" that arose from the text (Leonard, 1994, p. 57). The present study used a detailed narrative analysis framework that examined action, concerns, coping resources, and resolution of each narrative.

Thematic analyses and narrative analyses were conducted together. Analysis overall proceeded on the basis of the case, which in this study was an individual. Analysis of a case included consideration of all demographic and interview data for each participant. After each interview, each case was interpreted using thematic and narrative analyses and a case summary was constructed which addressed each specific aim. I often found it necessary to re-read text several times, until I arrived at an optimal understanding or interpretation of the data; this

discovery of optimal understanding was accompanied by an honoring of the voice of the participant (Leonard, 1994). From this detailed reading came the “exemplars” (i.e., small stories) that develop from analyzing the text; these exemplars illuminated the “meaning” of a specific event (Leonard, 1994, p. 59).

Interpretive analysis also evolved through the discovery of “paradigm cases”—the individual’s thick descriptions of an incident that increased my understanding of how an individual’s situatedness influences “actions and understanding”; Leonard, 1994, p. 59). Paradigm cases are unique to the individual and in this study, are interpreted based on the individual’s whole case analysis (p. 59). Finally, according to Chesla (1988), researchers should acknowledge the “family resemblances” that link a paradigm case to a specific clinical encounter that the investigators are attempting to explicate (e.g., language discordance; Benner, 1994, p. 53). Several factors were considered when evaluating interpretive findings—for instance, how both the researcher and participant met together at the interview with their pre-understandings about life, understandings that influenced the interpretive findings (Holstein & Gubrium, 2005).

### **Issues of Validity and Representation**

When using narrative analysis to study NES/LEP Latino immigrants, the validity of interpretive findings and the effect of representation and positionality on these findings were considered. With regard to the investigation, the most important factor influencing validity arose while conducting narrative analysis. The following discussion focuses on validity and how representation and positionality affected the interpretive findings.

Several factors were considered when evaluating interpretive findings—for instance, how both the researcher and participant met together at the interview with their pre-understandings about life that influences the interpretive findings (Holstein & Gubrium, 2005).

Because every participant experiences the world through a unique set of lenses, the participants' varied accounts were held to be true based on their many lived experiences (Holstein & Gubrium, 2005). Finally, I as the researcher interpreted the lives of others and was faced with the issues surrounding the "crisis of representation" (Denzin & Lincoln, 2005, p.18).

### **Crisis of Representation**

One central problem in conducting narrative analysis concerns how the researcher interprets the life experiences of "other" (Denzin & Lincoln, 2005, p. 21). In this regard, representation was considered in terms of race, culture, socioeconomic status, and positionality. Steps were taken by the researchers to address these issues to include engaging in reflexivity, co-creating and constructing text that incorporates multiple voices, and keeps the reader near to the text.

The researchers realized that the voices of NES/LEP Latino immigrants, like the voices of other historically marginalized populations, have been less heard due to their relative social position. Many health care institutions may not interrogate the quality and content of Latinos' language discordant clinical encounters, either because of lack of time or resources, or a lack of will to understand the patient's perspective. Based on my prior research, (Barakzai, M., Gregory, J., & Fraser, D. (2007). I was committed to exploring and articulating NES/LEP Latinos' experiences with reporting abdominal pain in language-discordant clinical encounters. *Foregrounding* race/ethnicity was important because of the clear evidence that they affect every aspect of health care (cite). As well, race/ethnicity were likely central to how participants "narrate, explain and make sense of the experiences of everyday life" (Lincoln & Denzin, 2005, p. 1118) including health care encounters. Latino immigrants live their lives within their multilayered Latino culture. Moreover, Latino immigrants interpret their lives according to their

backgrounds—which include, among other components, concerns, “possibilities” and/or “constraints” (Leonard, 1994, p. 47). In narrating their stories, Latino immigrants in this study, interpreted their experience with language-discordant clinical encounters in the contexts of racial and cultural discrimination, poverty, and lack of legal immigration status. Foregrounding these factors while doing interpretations was one way demonstrate social responsibility—a mode of conduct that I as a researcher supported in this study (Lincoln, & Denzin, 2005 ). Finally, interpretation of participants’ stories provided a rich and nuanced account of Latino culture and how that culture is supported or denied in health care settings; Using the frame of experiences with language-discordant clinical encounters around pain (Guba & Lincoln, 2005) helped illuminate many aspects of Latino beliefs and practices regarding their health overall.

Guba and Lincoln suggest that one key issue that impinges on validity is the “conflation between method and interpretation” (2005, p. 205). In this study, the researchers and participants “co-created” text to illuminate participants' experiences regarding the phenomenon being studied (p. 205). Analysis of text clearly identified and described my prior “understanding” or “bias” that might have influenced how the interpretive process was constructed (Denzin & Lincoln, 2005, p. 27). For example, my historical, social, and personal self, created my position and voice in the research setting (Guba, & Lincoln, 2005). My responsibility as a researcher was to portray NES/LEP Latino immigrants’ experiences with language discordance in light of their situatedness; my depiction took into account Latinos’ position in the world, such as lower economic status, marginalized status, and lack of legal status.

Finally, interpreting participants’ stories necessitated that I as a researcher be reflexive about my own background. As defined by Guba and Lincoln, *reflexivity* is the process of a researcher’s reflecting on her or his engagement as researcher (1985). Reflexivity demands that

the researcher critically assess how his or her background may influence the interpretation of participants' stories (Guba & Lincoln, 2005). The validation and authentication of participants' stories can be accomplished by recognizing the multiple voices within the text (2005). The concept of *voice* in narrative analysis has multiple dimensions—including, for example, the voice of the “author” and the presentation of the voices of the respondents in the text (Guba & Lincoln, 2005, p. 209). My background experiences and concerns were consistently interrogated as I analyzed each case. Finally, the text allowed each participant to be represented as his or her authentic self. Consequently, readers could hear how participants articulate their words naturally (e.g., readers could detect cultural nuances)—including the occurrence of any breaks in the continuity of the interview (e.g., periods of silence; Guba & Lincoln, 2005). Finally, this detailed representation allows readers to begin to understand how participants experienced their world.

### **Self-positionality and Self-reflexivity**

According to Van Mannen (1990), investigators must clarify their assumptions and pre-understandings by accepting that these assumptions and pre-understanding exist (p. 47). For example, as a third-generation, bicultural, documented Latina researcher, I brought all of my background and fore-having into understanding NES/LEP Latino immigrant experiences. One way I accounted for my particular understandings and biases throughout the research was to reflect on my previous experiences, beliefs and values each time I engaged in interview and interpretive processes (Holstein & Gubrium, 2005). I systematically journaled about my experiences and responses to the participants as the study unfolded. Considering the crisis of representation and finding ways to represent myself and participants enabled me to establish validity (Holstein & Gubrium, 2005). Study participants were encouraged to address my representation of their world by voicing any concerns about my interpretations (Guba & Lincoln,

2005). Finally, through my understanding of the validity as described in literature, I was better able to conduct research that was “*interpretively rigorous*” (Guba & Lincoln, 2005, p.205).

### **Summary**

GI disease is one of the most common health conditions occurring in the United States. To date little research has explored the expression of GI pain by LEP Latino immigrants in language- and culture-discordant health encounters. For Latino immigrants, the ability to communicate and describe symptoms of illness is essential for safe and correct assessment, diagnosis, and treatment (Diaz, 2009; Flores, 2006). Finally, this study used interpretive narrative analysis to explore the expression of pain by LEP Latino immigrants in language- and culture-discordant health encounters.



## Chapter 4

### Findings

For Latino immigrants, the ability to communicate and describe symptoms of illness is essential for safe and correct assessment, diagnosis, and treatment (Diaz et al., 2009; Flores, 2006). In this chapter, participants describe barriers to communicating their GI illness concerns to doctors and how they coped with those barriers.

#### **Participant's Experiences with Health Care Relationships.**

In this section, I present the findings from interviews with undocumented Latinos who had gastrointestinal illness. These stories include Latinos experiences with their doctors and extended health care staff within the United States health care facilities. In addition, cultural health care beliefs and practices, implemented by Latinos in attempts to overcome access barriers, and cope with the inability to communicate with their doctors is presented here.

**Fear of deportation/undocumented status.** A central theme that affected every aspect of participants' ability to communicate illness concerns to a doctor is the fact that at one time all of the participants were undocumented. Consequently, they lived in constant fear of being arrested by police and then deported to Mexico. The problems that arose from fear of deportation due to the lack of adequate documentation were evident in the participants' direct relationship with their U.S. doctors. For example, many participants felt extremely fearful while receiving GI illness care due to their undocumented status, and these fears created substantial barriers to communicating their GI illness concerns to doctors. Two examples of how lack of documentation created barriers to Latinos communicating GI illness concerns were described by a participant. First, she stated that she felt insecure and fearful because she knew that people like

her—residing illegally in the United States—were often characterized as alien criminals who were evading the police.

(S1) My experiences being here life is better than it is in Mexico, but like I say, we don't speak English, and we don't have insurance, and we feel like we are in jail. We can't leave anywhere.

(S1) I think it is because I am Latina, and I don't talk English. That is the barrier and because I don't have good insurance. I have seen that the people who have good insurance they get appointments and calls! They have papers that I don't have! Yes, this is my experience. I don't have anything against people who have good insurance. Ah if you don't have good insurance and you pay in other ways and don't speak English they leave you and won't work with you and won't tell you nothing. If you have good insurance and speak English, the front desk people get them and take them in.

Participants stated that they were acutely aware of their undocumented status every time they entered a health care facility to receive GI illness care. For example, participants were previously documented Mexican citizens or with full citizenship rights while living in Mexico. However, in the interviews, these participants noted that they were treated as if they were invisible because they were undocumented.

This informant suggested that the discrimination she experienced in clinic actually increased her symptoms and overall sense of illness.

(S3) It could be that because we do not have insurance, we are not citizens, or residents and this could be why. We do not get the attention that we need because we are not

citizens like the other persons that are born here, and all that I think, it could be that. Well you do not feel good but what else could we [undocumented Latinos] do.

Furthermore, participants clearly understood the severe constraints they faced every time they tried to get care while being undocumented and poor.

(S2) Well I felt real bad it leaves me the same. They tell me why go get more (healthcare) when you get the same. I say I just come here (clinic) they don't do anything [for] you [doctors] want me to die here. What we are going to do is ask God to save money so I can get the cure. Well, I don't have work where will I get money!

**Discrimination in health care delivery.** Participants witnessed the different ways that doctors provided health care to different populations of people (i.e., English-speaking Caucasian and African Americans) and suspected that, in comparison with the quality of care that English-speaking Americans received, the health care that Spanish-speaking Latinos received was of lower quality. Accordingly, participants made a conscious effort to stop wasting time and limited resources on this ineffectual and fragmented health care. For example, they believed that a visit to a doctor was equivalent to a visit to a pharmacy to pick up an over the counter non-prescription medication.

(S1) Because I don't have insurance, I am Latina and don't speak English (crying) well that is why I think is the reason. Because the program I am in and they looked at the paper (Medically Indigent Services Program insurance card) I had and studied it first. I don't know and they investigated the paper (MSIP) I had. I think that is the reason they would not provide me services I don't have insurance.

(S5) Well, yes, there are times that I think also with Latinos there are times that they don't get a higher diagnostic. All, only they just put Tylenol and that's it! I think why go to the doctor they won't be giving you anything only pills. I say if that's what I am getting, I can just go to the pharmacy! It is the same thing they don't have time I could go to the pharmacy and buy the medication that I believe I need to take!

(S2) You know what Madre (mother) you are very sick! But do you have papers (documentation)? They told me a doctor asked me like that, and I said no doctor I don't have papers. Yes, they ask if I have papers I said no, I don't have papers. Good papers, good insurance to cure me. They said there are doctors here tomorrow they said this is what they told me but it was like a little lie he (doctor) just went back around and left (the room). This is what they told me don't come back here, right there at the clinic.

(S8) She (doctor) said "You don't have insurance" I then said true but I want to go where I can make payments. Up to now, I have not heard from anyone. I responded no one has called me! I have not received any appointment. No one has made an appointment nor have I been referred to anybody where I can go and get the endoscopy done so that I know how I am doing. Nothing, I know as much as you do.

(S3) Well, I do not speak English. I am from Mexico. Then, I do not have any insurance. When you get there the first thing they ask you what kind of insurance you have and if you have Medi-cal. Oh no, it's for emergency only it does not cover you!

(S1) They treat us like this like we are nothing. Because, we have no value. Because of the insurance I say because they have and we don't have it. Those insurances pay them more.

Clinic processes appeared to participants to be selective for those who had certain kinds of insurance. It is possible that some of the participants may have been more adequately relieved of their painful abdominal conditions by proper medications and, for some, surgery. However, a key step in the diagnostic work-up was not available to physicians because of a countywide proscription of (esophagogastroduodenoscopy, colonoscopy) for persons insured under the Medically Indigent Services Program (MSIP), the state government program covering health care for the poor. Although it is likely that patients did not know of this county policy, their descriptions of healthcare received included inattentive care with little follow-up, open-ended appointments with few answers provided, and “stalling” approaches to care, including unreturned telephone calls and difficulty scheduling appointments. It is likely that some providers felt caught in a quandary knowing the proper steps in a GI pain work-up but not being able to complete all the appropriate tests. Analyzing the providers’ perspectives on this situation is beyond the scope of this study, but some of their behaviors may have resulted from disregard for the patient population, while other behaviors may have resulted from frustration and guilt about not being able to provide complete and proper care.

(S3) Not, no more [trust], anymore because I can see they [doctors] are just stalling. They are not hurrying. I would want this [esophagogastroduodenoscopy, colonoscopy] soon.

Many Latinos expressed a lack of trust in their doctors, interpreters, and health care institutions. This lack of trust led Latinos to stop asking questions about their GI illness and to give up on the expectation that doctors could provide a solution to their abdominal pain. Furthermore, Latinos left their healthcare visits feeling fearful, hopeless, and disheartened.

(S10) Well because they aren’t going to tell me anything and I will just get more angry, it’s the same! When I take those pills the heartburn goes away but something horrible comes

out of my mouth. I told that to my doctor so he told me to stop taking them. If I don't take them then the heartburns get really bad. No, nobody told me the risk of the medication.

**Inability to develop rapport with doctors.** Another institutional barrier to GI care was participants' inability or lack of opportunity to develop rapport with their doctors. Health care staff who examined their insurance and took notice of participants' limited English proficiency reportedly barred participants from ready access to the physician. As above, they were asked to wait, were not given follow up calls, and were generally treated differently from paying patients. Additional barriers included doctors who showed a lack of interest in the participants' illness concerns by providing limited information to their patients about how to proceed with their GI illness self-care.

(S5) Well, and then they changed her not sure why, it's possibly because of the money when the name of the clinic changed from Sequoia to Sierra Vista, there was no longer the same doctors. So, when I go they give me one [doctor] and then they give me another one and another thing is it takes a long time to get an appointment with the doctors! When you feel like you're dying in reality they do not have a fast appointment! I go there but who is there to touch you? You're just there. That's why I know that many times ultimately I pay for it they are all practicing doctors.

(S9) No, I did not get any medication Yes, it is not whole. But I did not get my treatment. Well they called me about the study but I could not communicate with him (GI specialist). Well I went to the office but all the front desk people said I can't communicate with him. I did not have a relationship I had a strain because there was no kind of communication!

(S10) You see one person then another, then another and you never see that first person again. The last person that sees you is who discharges you. That's the one who tells you [discharge plan] it's never the same person who sees you. I don't think they are nurses or doctors the ones that are just there in the emergency room. The helpers of the nurses.

**Lack of trust in doctors, interpreters, and Medical Assistance.** Participants' lack of trust in their doctors, interpreters, and the health care institutions were clearly communicated. Moreover, due to the lack of trust, participants stopped asking questions about their GI illness and no longer expected the doctors to provide a solution to their abdominal pain. Instead, participants left their health care visits feeling hopeless and discouraged about care in the United States. For example, several participants believed that medicine is a business therefore doctors get paid to keep their patients sick not cure their illness concerns.

(S5) No, because it give me a lot of nervousness with all of those things that I have heard about the hospital well I have fear they will kill me (laughing) because hospital at times the cure kills I would prefer to stay with this pain. I prefer to suffer to cope with this pain take the medicine. I feel it will help me more then to have a surgery! Yes, because one said this one is better and the other one said this one is better. I don't want the risk! Yes, the risk is much greater than coping with the symptoms!

(S1) I tell my husband I think this [health care] is going to kill me! [crying] because they [doctors] don't do anything for me. They don't show interest in helping me. [crying]. I say if they cure the people they won't have jobs. That's how they think: if they cure the person, they won't make money. That's why they don't help you. They say yes, yes that they will help me, but don't do anything.

(S1) Well, I don't believe the doctors anymore. I think they misdiagnosed me. They want to take this away to take that away. I think they do that to make money. They see me to make money.

(S8) Yes, neither the doctor nor the nurse! Not the treatment from him and not the treatment from her I didn't like anything from there! About my stomach they never did anything about that. Yes, I told the doctor about it. You wouldn't believe it, he paid no attention. He didn't make a note of it.

Participants believed that their illness concerns and care were constantly being passed off (patient dumping) to some unknown entity their student doctor (intern) identified as his "boss" [attending physician] who never contacted the participants to follow up. Participants recognized that being ignored by doctors and feeling invisible were factors directly linked to being an undocumented monolingual Spanish speaking Latino with no insurance. Participants felt that their doctors lacked a desire to know the participants personally due to time constraints. One participant describes a time when she clearly felt that her doctor lacked concern and did not pay attention to her illness concerns for years.

(S9) Well the story of what happened was when the doctor thought that I was pregnant and I wasn't pregnant I had an infection. He tells me that he couldn't give me antibiotics because I was pregnant. I said I do have a lot of people telling me that but you doctor how you can say that when you are my doctor when you see me every day. So, I justify it I tell the doctor no I can forgive others but you no! I have been coming to you for 8 years begging you to send me to get some test done on my stomach, and you come up with "you're pregnant", no! He said oh I am sorry no, I will send her to get the test done now, I am sorry. But I did feel very sad after.



(S9) Well it meant that it was sad and that he [doctor] really never paid attention to me. And it just showed that he never heard me because I had told him several times that my stomach hurt. He actually paid attention and noticed that my stomach was swollen because my stomach has not been swollen for months it has been swollen for years! Well the only thing that worked this time was that he actually listened and sent me to get the test done. Hum yea well from the later years if he would have listen to me and done the test before it would have been much better.

**Inability to access adequate follow-up care.** Another common theme among undocumented Latinos was their inability to receive adequate follow up care for abdominal pain. Participants believed that they were not eligible to follow up with their doctor because they were undocumented with limited or no insurance and could not pay their doctor for medical services. Although a few participants did receive a diagnostic esophagogastroduodenoscopy or colonoscopy, they felt they were never given an adequate diagnosis for their abdominal pain or an appropriate treatment option for their GI illness symptom(s).

(S8) If you so much as to make a suggestion to the doctor for example when I got sick, and before I got sick, I requested a referral [GI doctor] where I could make payments. I am sure there is some kind of a program, a place for referrals. To date, I am not aware of anything. No one care if the appointment was made, a referral. No one has told me call this number nothing! You have not told me anything and I remain so (sick). The only thing to do is pray to God for enlightenment and to help you with your condition this is what I have done all my life.

(S3) Well, I guess this doctor now that she [doctor] has seen this [illness she] just didn't give me a return appointment. She just saw the file and said I am going to make an

appointment for this [enlarged kidney, abdominal]. All for nothing she just gave me the paperwork.

**Physician approach to caring for undocumented participants.** Participants believed that in health care institutions, doctors and administrators suspected that the participants were undocumented because they spoke only Spanish. Participants felt unwelcomed yet they returned to the clinics and the ED for care, however fragmented, because they believed that in the United States they had a basic human right to at least limited emergency care. Their beliefs were consistently challenged by the discrimination they experienced in the U.S. health care system.

Participants believed that doctors and health care staff should be aware they are caring for undocumented Latinos who are sick and often in a state of fear and about their well-being. One participant felt especially degraded and humiliated by her GI illness care. The participant clearly communicated below that her GI illness won't improve until she stops accepting more fragmented and stressful care.

(S8) After that I did not go to the doctor with their attitudes and how they treated me. I had to wait in the patient's room over 35 minutes naked in the patient's gown and that just didn't settle well with me. I was full of tension I was nervous instead of feeling better; I left more mad and worse and just never went back. Hum that they do not have compassion for the sick or give you the attention you need. And if you are going to be treated that way why go there or return?

Furthermore, participants were keenly aware that their doctors' approach to their GI illness care was harmful because it was not comprehensive. Therefore, participants did not accept or use their doctor health care advice.

(S12) I was going to say that the doctors are like in a competition to see who sees the most patients instead of taking the time to listen to the symptoms of the patient. They come and say, what are your symptoms? I respond it's my stomach. What do you feel? I say I feel this and that and, when you start talking about how it is also causing this and that, then all they say is I am going prescribe this medicine. All the symptoms are there but the doctor a lot of times like he is in a competition. The more the symptoms the less he listens to the problem.

(S10) The same thing, the doctors just wait for you to get really sick. That is what I am waiting for to get really sick to get medical attention. Because not right now when I go I want to talk about it but I forget what I was going to talk about or ask the doctor I feel weak sometimes and I forget to tell them.

**Feeling profiled by doctors.** One participant described how she tirelessly and repeatedly sought care for her unresolved abdominal pain, but her requests for relief of pain were disrespectfully dismissed by the treating physician. The scenario presented here suggests that the physician suspected the participant was taking drugs inappropriately. In particular, his letter discharging her from his practice suggested that he believed that she was fabricating or exaggerating her pain complaints in order to get prescriptions for her pain medication. It is well documented that diverse populations are undertreated or inadequately treated for pain (Wu, Banks, & Conwell, 2009). It appears that with this particular patient, the physicians overconcern for drug abuse led to a grossly inadequate response to the participant suffering and symptoms.

(S9)When I was with that doctor he gave me a lot of treatments, and then he said that I was a crybaby that I was crying all the time. He said there were other women that had disc displacements and they were still working, and I was always complaining! I told him well

that's what you think, but I am in a lot of pain and I am coming so that you can give me something to stop the pain. And (if you helped me) I won't be coming to see you often! So, he told me no [no care]. So I came home and then he sent me a letter saying that he couldn't treat me anymore because I was being irresponsible with my treatment!

**Reporting feelings of being harmed by care.** Several participants felt harmed by their doctors' care. For, example, after GI surgery, the participant lost her ability to safely consume various foods from her cultural diet (i.e., milk, chili, meat) without provoking severe GI illness symptoms. She believed that the doctors harmed her body with their operation and treatment modalities. Consequently, the participant experienced a great deal of anxiety and depression after she allowed strangers or doctors to alter or change her body permanently using their medical model and treatment modalities. The participant believed that her GI illness care and treatment damaged her body and that her abdominal pain had become permanent because of her doctor's care. Therefore, the participant felt that her doctors' ineffective health care and medical interventions left her feeling that she had been experimented on by her doctors.

(S1) What they have done for me? My gallbladder it used to not hurt. They took out the stones. I used to drink milk and it did not bother me and now it does. Eggs, I used to be able to eat them and it did not bother me and now it does. Everything they have done to me. To me this is very serious because I have a pain [so much] pain that they have even given me morphine. I say it is serious. I did not have this pain before. I say this is serious because I can't eat anything anymore. Water, if I drink cold water.

Furthermore, the participant felt misled by her doctor after discovering that her doctor prescribed a medication for moderate depression. The doctor did not inform the participant that he was treating her for depression and she did not complain to her doctor that she felt depressed.

Consequently, the participant was shocked to discover that her doctor prescribed a strong depression medication for her GI illness concerns. The participant felt harmed and lied to by her English-speaking doctor. Furthermore, she experienced disturbing side effects while unknowingly taking a depression medications, experiencing unexplained drowsiness while driving to and from work and while working around machinery. Although the participant had concerns about the side effects of her medication she was unable to contact the doctor who prescribed the depression medication to follow up her concerns. It is possible that due to the participant's chronic abdominal pain and previously failed medical treatments, her doctor believed that the participant's GI illness concerns were possibly a result of a "*functional gastrointestinal disorder*" and therefore prescribed depression medication in the presence of language and cultural barriers (Tornblom and Drossman, 2015).

(S1) It hurts me when I don't sleep, it's the pill antidepressant I think, but I don't know. In the early morning for short time when I take those pills it provokes much sleepiness with the other medications for depression. I've tried to talk with the doctors but they don't return my calls! I left messages for the nurses but no one will call me back! I get to sleepy and it's hard to drive at work and stay awake. The doctors who gave me the medicine did not call me back to fix this. He never told me what the medicine was for or what it does for me.

Another participant clearly believed that her doctors' recommendation that she change her cultural diet was not an appropriate treatment for her GI illness concerns. In fact, she too felt harmed by her doctor's care.

(S7) I became very skinny! When they [doctors] gave me a changed diet I was not able to eat anything. I could eat everything [before]. So, I stopped the [doctors] diet because I felt more sick. I couldn't do it! I am too skinny and delicate because I can't eat anything everything it's a lot. I ate everything every day [before the doctor's treatment] now I can't eat nothing? I have pain and live a lot with pain for many years! There are times that I cannot get up because I have too much pain.

**Fear of advocating for quality care.** Furthermore, participants did not advocate for safe, adequate GI illness health care because they feared being denied any form of health care in the United States.

(S12) Ultimately you cannot say anything to them because they look very serious! You have fear to speak to them, one just has to wait a long time. You cannot tell them that to speed up no, they will say you know what if you put this problems you can buy a bottle of. They have sayings there [in the clinic] if you bother the people [receptionist, medical assistance] you will have to pay \$15 dollars for bothering (sign posted in the health care facility was interpreted by the participant as a form of punishment if she tried to advocate for good care).

(S1) I feel like I am nothing to them (doctors), like they have all the reason [information] and I don't want to talk much because I don't want to get into any problems and make them mad because, they might not want to help me.

(S10) No! I don't know I'm not going to be asking who are you because then they [doctor] are going to tell you who are you?

**Ineffective and fragmented care.** Participants provided countless examples of ineffective and fractured GI illness care when they returned to their doctors for more diagnostic exams that again did not produce a diagnosis for their abdominal pain. Clearly, participants did not think that medication alone would be a solution for their GI illness concerns. Participants described repeated experiences of being cycled through the clinic and the emergency room while suffering from what they believe to be severe GI illness symptoms such as vomiting and diarrhea just to be sent home with no solution for their GI illness concerns.

(S3) No, because if they were giving me proper treatment, they would call me saying you know what your results are. Come on in so we can tell you how they [diagnostic test] came out. I am afraid. I have been to the Kearny Street clinic, and I got the same treatment. I was at another [health care clinic] over by road 145 and it was the same. The same. It is all the same. The [clinic staff or doctor] have never called. If they were to call, they would be paying more attention because they are calling to tell you that you are not doing well and we need to take the next step but they don't; they don't do it!

(S1) About, about five–six times that I have gone to get help. So far, that I have been at the doctors. I've got three or four times to the emergency room vomiting and with diarrhea. The only things that they have ever ordered were test that I am told were fine. I had done that but there was no solution, yet again.

Furthermore, participants were convinced that doctors did not do enough to investigate the cause of their GI illness. In addition, participants felt denied their right to be sick every time their doctor told them that the exams were all negative and that the participant's health was perfectly fine. Participant's doctors repeatedly ignored their need to communicate their illness

concerns. Instead, doctors based the participants' GI illness care on results of repeated and limited diagnostic exams.

(S10) They are running around they are not going to give you explanations. If I had several millions of dollars I would not go with those doctors. I don't know if I would have known that they did not want to give me treatment well, I don't know. I don't know, I don't think things would change much because I asked them questions and they know they are doing things wrong but they won't admit it. That I could find a doctor that would not be lazy that would study my case correctly. Well bad is that word means, I am mad and sad with rage! All of that is covered with the word bad. One time well they gave me well they send me for blood test and when I go they still don't have the results. Well bad is that word means, I am mad and sad with rage! All of that is covered with the word bad. No, well cancer! [due to inadequate care]. That I could find a doctor that would not be lazy that would study my case correctly.

Participants believe that they did their part to get better. For example, most participants removed cultural foods (i.e., chili and coffee) from their diet. Yet, doctors did not take time to inquire about the changes participants had made in their diet and lifestyles instead their doctors were quick to prescribed medications.

(S3) For me for this pain they only gave medicine to help me with the food I eat but it did not help. I cannot eat anything, anything everything that I eat right away I feel sick. I cannot drink milk, cheese, cream, meat, nothing, nothing. I can only eat beans or things like that nothing spicy because I feel like if my stomach is burning and it hurts a lot. I was told that it could be the gallbladder or gastritis or maybe I have already ulcer. Yes, all most every day it hurts is very rare that my stomach will not hurt but the pain is there every day.



(S1) More focus on my health! What are you eating how are you? She made me feel really bad about my health. I think like what I am eating? I have a friend that said, what do I go for? (crying). I think it's their fault cause. I didn't have this pain. The first time I went was in September. I went to the hospital. They gave me pills, and when they gave me pills that's when I started getting the pain.

Participants reported that although they accessed clinics and doctors in the United States, they received minimal follow up care. They were dissatisfied with their inadequate care because they knew that the quality of care in the United States was good, yet they received scant follow-up exams (i.e., blood pressure test) that were unrelated to their GI illness pain. Moreover, participants were annoyed by the doctor's pointless assessments that didn't bring them any closer to the cause of, or the solution to their GI illness pain. Again, the participants communicated their dissatisfaction with their doctor's ongoing lack of attention.

(S1) The quality of care is good. It's just that nothing is done to me. That is the only bad thing about it. What good does it do me to constantly be checked on and have my blood pressure checked? That's all they know how to do. I'm not given anything to get rid of it. It goes away a little with morphine. Up to the highest, the highest dose for pain because I can't bear it!

(S3) I wasn't given a return appointment, nor did she say come back see how you are doing or send me somewhere, nothing. Nothing, nothing—because I am the one that has to be calling to see if the results are in. She says that they don't have to call me; I am the one that has to come in. They will not call me.

**Frustration with the care experience.** Participants were very frustrated because their doctors did not take into consideration the fact that G.I. symptoms were often debilitating, yet

participants were left without a solution. For many participants, the most frustrating part of the care experience was risking deportation and possible injury to self for inconsistent and ineffective GI health care. Consequently, several participants felt their care was provided in hostile environment with unfriendly health facility staff.

(S1) Bad means, worry, sadness, stress. Yes, stresses because I can call and call doesn't go through. It says "if you want to an appointment push number 1, if you have no problem now just make 1." I leave message and no one returns my call. Now this worries me.

(S4) No, well I tell you they don't know they think it's like gastritis. If I don't think this is I felt like it's not gastritis that it is an illness bigger but who knows? That's why I told my wife that by the end of the year we're leaving.

As one participant stated that unfriendly and confrontational health care visits make it impossible for her to communicate GI illness concerns to a doctor.

(S8) He said it is for this for this and for this and he gave me four medicines but then he ended up only giving me two so then I left. But I did not like the doctor's attitude the nurses attitudes either so I did not go back I even told the secretary you should not even be here because of that attitude to attend to people it is very bad! I ask you a simple question and you are treating me very bad. You should not be here because first of all when you go to work you should be there because you like it but you, you are here because you have to be! So, now I made an enemy and I am not going to return. And then I changed to the one on M [street] all the people are different but I do not like the doctors.

(S10) No, nobody spoke with me. No, nobody told me anything about it. No, nobody told me anything about the medicine. All they did was give the medicine to me. Yes they wrote

me a prescription. No, no I just don't think about it, why? I don't dispute this I don't think about this. Yes, yes o I think it's better not to take a lot of medications but the thing is the hospital is the same no nobody gives me one[diagnosis].

**Language Barriers.** Language and cultural barriers negatively affected the quality of the participants GI illness care and their well-being. For instance, participants reported that language barriers resulted in untimely care, misdiagnosis of GI illness, and several ineffective treatments, including invasive abdominal surgery. For example, in the following, one participant was provided a telephone interpreter service. She was set up for surgery although she clearly had residual questions, and did not seem to understand the risks and possibilities of the surgery she was being offered. The participant felt hindered by having to communicate through an interpreter. For example, the participant could not communicate her symptom experience and her distress via a telephone-interpreter. After surgery, which did not resolve the pain, the participant continued to feel as if her care was constrained by the language barriers between her and her physician.

(S1) No, the doctor speaks in English. How would the doctor be able to tell me? They told me on the telephone, and I believed that, well they put me in surgery they were going to be able to make this pain go away.

(S1) Well, frustrated. I feel bad because I can't [speak English]. It's because I want to explain it. I want the doctor to tell me directly. The doctor like in Mexico directly. Doctor, this is what I have and it's not possible. Only a person needs to come, or over the phone they translate.

Language barriers prevented one participant from utilizing her limited insurance. For example, her English speaking GI specialist prescribed a medication that was not covered by the

participant's insurance. Generally, a patient can phone their doctors office to request an alternative medication that is covered by their insurance. However, language barriers prevented this participant from communicating with her doctor, or anyone in the health care facility. Consequently, the participant did not get her medication or begin her prescribed treatment.

(S9) It is very important to say it yourself it is the way better! When they sent me to the specialist about my stomach right there I struggled because of the language. I struggled a lot the specialist gave me a medicine but they never accepted the prescription at the pharmacy and always they called. I tried to call him too so he could change the prescription and but I never seen the doctor.

(S8) They only talk English and what do I need an interpreter if they don't understand me or tell the doctor what I am saying or how I am feeling to asked questions. And that is all they have over there (CSV) doctors that only speak English.

Participants felt that their GI illness assessments were consistently inadequate, ineffectual, and disjointed and that their GI illness care was substandard. Consequently, they believed that going to the doctor in the United States was frequently a waste of their time and of their very limited resources.

**Feeling distrustful of extended health care staff.** Another barrier to communicating GI illness concerns was Latinos inability to develop a rapport with their unfriendly doctors, medical assistants and the receptionists. Latinos felt discriminated against by the extended health care staff who examined their insurance and were aware that Latinos were monolingual Spanish speaking. Furthermore, Latinos described feeling oppressed by second generation Spanish speaking Latino medical assistants and the receptionists.

(S8) A nurse [medical assistant] who is mean and who speaks rudely to you “sit here and put this (gown) on”! I told them good morning how are? They don’t even smile they give mean looks so I said no more! What I just mentioned get angry! I became furious because I felt so sick because they put bad attention to me. I asked myself why come just to get frustrated. Better to just stay home.

(S8) I did not like the doctor’s attitude the nurses [medical assistance] attitudes either. So, I did not go back. I even told the secretary you should not even be here because of that, attitude to attend to people it is very bad! I ask you a simple question and you are treating me very bad you should not be here because first of all when you go to work you should be there because you like it but you, you are here because you have to be! So, now I made an enemy and I am not going to return. And then I changed to the one on M [street] all the people are different but I do not like the doctors.

Participants believed that both forms of discrimination—disrespectful and inhumane health care by their doctors and extended staff—were enormous barriers to their receiving good GI illness care. One participant described how terrified she felt after leaving the health care facility because she believed that the medical assistants and receptionist would notify INS that she was undocumented. Lastly, the fear of the extended health care staff had very negative consequences on the participants’ health and health care.

(S5)Yes, the cycle, well for me also I working on my papers. I think this too is a main cause many times we are stressing because we are afraid because we don’t have the documentation! With the receptionist because the first person you see in then clinic is the receptionist you don’t go with the doctor! I think it not so much the doctors I thinks it more

than anything for example with the receptionist for me this is a more a more serious fear more large with the girls then with the doctors.

(S5) Yes, quickly when its people of your same race they treat you worse than with an outside race! The treatment doesn't look like the treatment of other people from the same race the Latino they treat you worse than other persons that they truly treating and helping! And there, I think there the first fear, the first fear is with the receptionist because I they have my telephone number and I have fear that they will call to say who I am and they will come and get me.

Okay, I have more fear with them because they are the first persons to get all of your information your address your telephone number and your Social Security number and when they come for my social security well I don't have one! Well no, no I don't know that. This is why one gets afraid! No, no, with a lot of fear, because! Yes! Yes because fear is what brings on the stress. Yes! Yes it's a lot!

Participants experienced a breakdown in expectations in the quality of the relationship with their health clinic. For instance, participants often felt unwelcomed and criticized by doctors and other health staff for returning repeatedly to the health care facility for a solution to her GI illness care. One participant was mistreated by extended health care staff leaving her so upset and shocked that she could no longer participate in her health care.

(S8) Ok, I went there (Clinica Sierra Vista) and the people their treated me like I was an animal, really ugly! I asked for an interpreter to be able to ask my questions but they had bad attitudes and when there was a nurse present while I was to see the doctor she would talk very rudely saying "why did you come"?! And what is your problem?!

Latinos expected their doctors to care for them and provide knowledge about how Latinos should overcome their illness concerns. Instead, there was a breakdown in the expectations by the Latinos from the type of relationship they expected to have with a doctor.

(S10) They [doctors] are shameless, what can one do? Just shameless! They have bosses who tell them to do that. I was angry but what can you do but put up with it. There's nothing else to do. Like three or four times, but not sure for the pain. When I am really sick, I will go. My doctor tells me, well that I am already old. I am use to them telling me the same thing all the time, they don't give me an exact diagnosis. They just give me pills they have never really given me an exam. The most detailed exam they did through my mouth (esophagogastroduodenoscopy).

Having a Spanish-speaking Latino doctor did not guarantee that Latinos would feel cared for or experience effective communication. Hierarchal relations and lack of concern expressed by physicians formed barriers to care. Latinos did not feel that their Spanish speaking doctors show concern for their illness concerns.

Participants described feeling "*disrespected*" and treated unfairly by their many doctors and unable to convince their doctors that they were really sick. The example is drawn from a participant who explicitly discussed how having a Spanish-speaking Latino doctor left her feeling blamed, disposable, and uncared for. The participant felt that doctors suggested that the participant ate foods that caused her illness. Moreover, she believed that doctors ignored her request to follow up care on her GI illness and medications. Last, the participant wanted the doctor to stop the harmful comments that she injured her own stomach by eating everyday cultural foods (i.e., chili, fatty meats and eggs).

(S1) She [Latina doctor] talked to me very rude, belittling me. She made me feel very bad. [Imitating the doctor] “What is your problem ma’am what is that you have!?” Like with a lot of pride. She began to explain don’t eat this [cultural food] and don’t eat that.

I was feeling guilty. I don’t eat the things that can harm me. I take care of myself a lot. Right, now I drink Soy and I don’t eat eggs because they have a lot of cholesterol I don’t eat meat. She also told me I’m fat and I need to lose weight. She told me very rude like that! The food you eat makes you sick and that is all they say. She [doctor] looked like a Latina, this person. She didn’t give me any hopeful words or tell me what the problem is. [She] did not tell me what the problem was. Nothing, just like this serious [unfriendly, unsympathetic] just serious.

The participant, who was suffering from severe GI illness, was left unattended in the emergency room and ignored for hours by doctors. As a result, the participant described feeling mistreated and discriminated against both by the provider and by the health care institution as a whole. Although the participant was able to access her local health care facility, she felt that she was unable to receive effective and timely care. The participant stated that, given her inability to speak English and limited insurance, she believed that it was impossible for her to effectively navigate the convoluted system posing as a documented person. The participant stated that she was aware that in the background of every health care encounter were “*bad papers*” [forged or fraudulent immigration documents] that placed her in a vulnerable position in which she was not able to advocate for effective and safe treatment.

(S1) I am scared I have fear! They need more professionalism. I don’t know how to explain um to give us [Latinos attention]. They are people, but we are people, not animals to be left last.



**Interpreters.** The Latinos recognized that interpreters were not translating their GI illness concerns verbatim to their doctors. Furthermore, Latinas suspected that interpreters did not provide their English speaking doctors with a complete Spanish to English translation to be used to communicate illness concerns to their doctors. Consequently, the demand for English-speaking doctors to “give attention” (communicate) with Latinos about their illness concerns was greatly reduced or non-existent. Latinos concluded from previous experience that speaking to their doctors via an interpreter encouraged their doctors to disregard their illness concerns. Therefore, Latinas viewed interpreters as a communication filter or regulator of the Spanish to English translation of the participant’s illness information, because the interpreter was the only party who knew both sides of the participant’s health–health care situation both the participant’s view and the provider’s view.

(S12) Ah, I believe that it does because hum it influences because a person that is in the middle of one interpreter or the other are not at times saying what you are saying and giving other information at times they omit words or true information. I don’t, I don’t get the information after[ leaving the clinic]. Well at times I won’t go back because I tell the person and they won’t repeat what I am saying, they won’t repeat it.

Lastly, Latinos were aware that language barriers left their doctors with insufficient medical history to effectively treat the Latinos GI illness.

(S1) For one, they [the doctors] don’t do anything for you. They don’t give me medication. They told me that they were going to operate on me. I see that they say one thing and they don’t follow through with their word. They don’t keep their word. Ever since they found this (GI illness) they said they were going to operate on me. Twice they have told me this.

And this frustrates me, it depresses me. That they say we are going to operate on you. We are going to help you. And don't do anything.

Furthermore, participants found that communicating their illness concerns to their doctors created greater stress and illness for the participants over time. As a result, participants felt neglected and uncared for by their many doctors.

(S3) Until now I cannot sleep. No it is not the pain [that causes insomnia] I feel very sad. It's not that [pain] I just feel sad [feeling sad caused insomnia].

**Feeling othered.** A major barrier to reporting GI illness concerns were doctors who treated Spanish-speaking patients like the “others”. Participants often felt othered by their many doctors, which lead to a breakdown in communication regarding both their nationality and culture when they entered the American health care facility. For example, Latinos could not speak with their doctors in their native language to communicate their cultural health care beliefs and practices. Moreover, the participants felt mistreated by doctors, and that this mistreatment was based on the participants' nationality and language. The participants felt that, because of their ethnicity and lack of immigration documents, they did not have a right to advocate for adequate, safe, and respectful GI care.

(S1) I feel bad because we are in a country where English is spoken. Speak English, speak English we are told. How long have you been here for ma'am? I am told. I have been told you don't speak English? So many years and you don't speak English?

(S9) It is so necessary to speak English and I understand that. The doctors and people say that we are in a country where you need to learn English. My tears build up when someone tells me that because you say that is not true it's not that! I want to but I have not been able

to do so. I have I tried I have gone to school and I have tried but have not been able to learn English. It is difficult because there are people that want to learn it English but it is difficult to learn it. (laughing)

Participants endured dehumanizing health care because their entire care experience was underpinned by their undocumented status, inability to speak English and the enormous fear of being caught by the police and deported by the Immigration and Nationalization Services (INS). Furthermore, undocumented participants would not knowingly risk being deported in exchange for demanding better GI health care.

(S1) I would like to live a normal life to not have this pain. To work. I like to work for my children. I would like things to be better because there other people know that have this problem. We are all people, we are people. For them [doctor] not to discriminate against us because we are undocumented. We are people as they are people. We feel the pain in our body and in our soul.

**Acute Illness Experience.** Several participants presented to the emergency department complaining of severe abdominal pain yet these participants were left in the waiting room without an initial history and or physical assessment for an extraordinary amount of time. After long delays for assessment of their severe abdominal pain or pain control in the emergency room setting the participants' became distraught and were inconsolable. Spanish-speaking Latinos have a history of delayed health care. A recent study found that ethnicity, combined with limited English proficiency, greatly increased the risk of Latinos experiencing a perforated appendix. Furthermore, communication barriers correlated with delayed assessment of abdominal pain symptoms with higher appendiceal perforation rates in Latinos with lower English proficiency (Levas, Dayan, Mittal, Stevenson, Bachur, and Dudley et al., 2014). Consequently, given the

association of appendiceal perforation with increased morbidity, the reporting of ineffective, fragmented and limited GI illness care by the study participants is a matter of concern. One participant's experience with delayed GI assessment follows.

(S3) No, I do not know the nurse. She only come out one time and told me that the doctor was going to call after he had time and they are going to call you. They are going to call you. And all day went by and the night. No, I was not in the room. I was in front of everyone. I was in the lobby with everyone. I was there all day, but I was never taken to a room. I was never taken to a room. No, I was not in a room. I was just outside (lobby) sitting or standing up. I was (finally) taken to a room at 11:00 p.m. and I was left in the room for another hour without the doctor going [into the room] to see me when I was in the room.

In this instance, the patient was so distraught about her pain that she had limited ability to advocate for herself. The delay in being seen not only prolonged her suffering, but additionally subjected her to the embarrassment of having to suffer in public. It's clear she felt surrounded by strangers, and that she and her family lacked any privacy in trying to cope with her extreme pain.

(S1) When I went to the hospital there were a lot of people, and I waited like 4 hours to be seen. And my pain was so severe that I practically fainted, and they wouldn't attend me. I was crying from the pain. They were helping the White and Black people, and they wouldn't help me. And when a lot of hours went by, they helped me. Because I don't have insurance, I am Latina and don't speak English (crying). Well, that is why I think is the reason. Because the program I am in and they looked at the paper Medically Indigent Services program (MSIP) I had and studied it first I don't know and they investigated the

paper (MSIP) I had. I think that is the reason they would not provide me services. I don't have insurance.

**Fear of incarceration while being cared for.** Most participants quietly remained in the background of health care visits, attempting to avoid being exposed for their undocumented status or for illegally gaining access to the Medically Indigent Services program (MSIP). During this study period, undocumented persons living in Fresno County were excluded from applying for and receiving MSIP. But some participants disclosed that they accessed support from the MSIP by using a family member's social security number to get health care, work, or food. For many Latinos the experience of GI illness care was accompanied by immense fear of being incarcerated and deported. Therefore participants could not worry about how many failed medical treatments they received or that they lacked follow-up care for GI illness; their concerns about being undocumented prevented participants from feeling safe enough to advocate for good care. One participant explained her experiences of being undocumented, uninsured and in constant fear of being incarcerated in the United States as follows:

(S1) We drive carefully with fear of the police because we don't have a driver's license to drive. But going to the doctor you feel the same case and they don't listen to you because we are Latino we don't speak English we don't have insurance that is how we feel.

Another participant felt unsafe in the health care clinic believing that the second generation Latino clinic staff would not keep his undocumented status private.

(S4) Well in Mexico its Mexico and because you're in your country with your people [extended Latino health staff] you're the same there. Here there is a lot of people are different and even your own people don't like each other! My wife works not far. She worked for 16 years and in 2008 (crying) someone called the immigration to take her

(laughing) but why? Well they fired her because they [immigration] tried to take her!

**Feeling diminished by the doctor's care.** Clearly, participants felt insignificant and invisible when cared for by their many doctors. Moreover, participants believed that real doctors were being used to find solutions and cures for English-speaking American patients but that undocumented Latinos were ignored or left to be cared for by doctors in training.

(S4) So I said I[will] just go home then continue being the way until I can't take it or if it comes [abdominal pain]. The day that I can't take it then I go to the emergency and if I die then I die because that is what they provoke they don't see us!

(S9) I had a time when the doctor walked in the room, and he had a prescription already filled out. And I was like wait a minute, doctor. I feel really sick. And he would say, "I know—I have a prescription here!" So you get a little upset so you tell the doctor now doctor, I was not out there waiting for two hours so you don't check me! You can at least give me five minutes sit down please!

(S1) They are not doctors [they are] doctors still studying. And I think they put them for the Latinos. For these people they see these doctors (student doctor) because they have MSIP and for the ones that have the insurance they see the [real] doctors.

(S3) It's only for the people that have insurance and right now she cannot take me. Ahaa, it won't they [Community Medical Regional Center GI DEPT] are not taking any patients with (MSIP) only private insurance. That's why I am going to remain in the same condition until I die. They don't want to treat me. Well nothing just wait and see.

(S9) No well I feel bad because I insisted in calling but since I didn't know English they would always say no there is no one that can speak Spanish. That is why I went personally to see if I could find someone that spoke Spanish. But no, they said that they could not see me the doctor was busy.

**Health care competes with paid employment.** Participants often work long hours for low wages and many are forced to work on weekends. One participant was self-employed as a gardener and worked long hours for low wages. Another participant was the sole provider of her family after her husband suffered a catastrophic accident and now lives in a vegetative state. The health care facilities that provide care to undocumented Latinos [farmworkers, laborers] have limited hours and excessive wait times. Consequently, Latinos feel overwhelmed every time they forfeit wages and risked losing their job to seek health care.

(S3) I have been going and taken treatment. I was sent to Fresno to have studies done. I went on Thursday I asked permission on my work, I only last my work day (decreased work hours). I went and when I got there I was told that the doctor changed my appointment. I only went to lose my time because I was told that my appointment for those studies were changed by the doctor and that they were going to call me to let me know when I was going to have another appointment. This is why they send me to have done many studies but like I telling you I went but my appointment was cancelled! I felt sad because I got up at 6 a.m. to go to work and I work 6 hours and I left work to go to the appointment for nothing. I told my sister in law because she ask me how was it and it was not good. I got mad because I did not finish my working hours and I did not got to sleep and I went all the way to Fresno for nothing because I was not attended and the studies where not done. I was mad because I was not attended and the lady only said "I am sorry"

that was the only thing that the lady said. They should have called me but they did not call me. That, I went it was worthless because I just went for nothing. I am still waiting to reschedule the appointment, and the doctor wants me to have those exams done to find out what is going on.

(S10) One time I went to the hospital when I did not have insurance. I came out of the [ED] at 5am in the morning after coming in at 2 o'clock in the afternoon and all they gave me was a spoonful of Maalox!!One spoonful of Mylanta! No, they gave me a spoonful of Mylanta then gave me the bill!

### **Personal Characteristics**

Participant shared common characteristics of low health literacy, low income and limited resources based on geographical residence. These shared personal characteristics had a negative impact on the participant's physical and emotional health and their health care.

**Low health care literacy.** Because of their ethnicity and language barriers, participants felt like outsiders waiting for an invitation from their doctors to participate in their GI illness care. Furthermore, the medical model doctors used to care for the participant's resulted in the inadequate patient-provider clinical communication consequently precluding the providers from being adequately informed about their patients' illness concerns. For instance, participants felt the use of unprofessional interpreters by their doctors left them unable to communicate their cultural illness story; in the reverse, they felt that vital information about their illness was left out by interpreters, leaving them in the dark about their illness. Participants became aware that both their doctor and they themselves were uninformed about the GI illness during the health care visit resulting in more fragmented care. Lastly, participants felt that they wasted very limited resources on health care that did not bring them closer to a cure.



(S5) Yes, without knowing the cause [of my GI] illness, right? That I feel when I look for help well I feel like I am blind and deaf because I don't know the cause of my own abdominal pain

(S5)I think in the moment that you are sick the quality is good but deep down I don't think it is good because no, no you don't have the precise diagnostic of what you have. It hurts because of this [no diagnosis].

**Low income.** The participants in this study were unable to overcome the enormous barriers associated with being undocumented, uninsured and poor. As a result of their status, participants believed that they were not given proper diagnostic tests for their debilitating GI symptoms. Some participants were explicitly informed by their doctors that being undocumented and uninsured severely limited their diagnostic options. One participant described how her low income negatively impacted all aspects of her health care. She experienced a great deal of anxiety looking for the best care for her limited resources. Additionally, she felt harassed by the eligibility worker and the receptionist at the health care facility to pay her co-payment or risk not getting care.

(S12) That I have access to other clinics to go to no! In reality, you look around where you are able to afford economically to pay for the doctor's visit. That's what you are looking for. There is many who are very expensive. Like me, I don't know of many clinics that I can go to ( static in the microphone) go to this doctor his fees are cheap or there is times when people tell you "I know of a doctor who charges not very cheap but he listens to you pays you more attention." But in reality one doesn't have sometimes you just don't have it [money] it's not economically possible to just get any doctor.

Then you go and apply for low income resources and since my husband works he is self-employed sometimes, he earns good money and there is months where he doesn't make any money! They [receptionist] then ask you for check stubs and it happens to be the month when he [husband] is making good money and I don't qualify. Next month comes around and you don't have any money and nobody takes this into account, nobody! Medical doesn't take this into account. If you are working and making good money when you are supposed to report earnings you don't qualify and lose out on many benefits. And they tell you "you have \$20 dollars?" Sometimes you go to the clinic and they tell you: "I don't believe you don't have twenty dollars it's only \$20 dollars, not \$100!" They don't take into account one's economic situation sometimes you don't even have a dollar!

Participants felt that having low income greatly decreased their possibility of their doctors providing them the best health care options. Lastly, having documentation did not improve the participants care when they suffered from poverty.

(S5)They don't give options that I can choose. What more is good for me! No, never spoke to the doctor if there were options but many times too ah I am limited asking questions because I don't have sufficient money.

(S10)Well, when I did have papers I wasn't getting treatment either because well because you would have to give them money. One would have to give them money to cure me. Well yes. Also the insurance it doesn't pay everything. Well yes, when they gave me the machine to check my sugar but I could not pay for the other part (glucose strips) so right now I'm not even checking it. Yes, but the machine yes I have it but those cards those I don't have. Two dollars for one card. So, I have the machine that was given to me from the

clinic over there (CSV). But not the other one stuff [glucose strips]. I wouldn't be able to say [glucose levels] because I don't know.

**Limited resources based on geographical residence.** In Fresno county, undocumented participants were not eligible for (MSIP) during this study. In addition, the majority of the participants could not access any type specialty care (i.e., esophagogastroduodenoscopy), regardless of the severity of their GI symptoms, unless they had a medical emergency such as a GI bleed. In fact, a GI department referral specialist (who asked not to be identified), confirmed via phone conversation that the GI Department within Community Medical Regional Center (CMRC) located within Fresno County had informed doctors via a letter that all patients with MSIP who were found to have a negative Guaiac test (i.e., no microscopic blood in one stool sample) documented in their medical records were to be removed from the wait list to receive a diagnostic test (esophagogastroduodenoscopy). However, none of the participants in this study were informed that they had been removed from the wait list for gastrointestinal diagnostic examinations.

(S3)No! No, because I have to pay the rent and all the bills I just couldn't do it right now. No, not right now. Because the doctor told me it was closed that she cannot send me there because they are not taking (the uninsured and undocumented patients). It's [colonoscopy and esophagogastroduodenoscopy] only for people who have insurance, and right now she cannot take me.

(S4) First, we eat, then we pay the bills. I have no money just to live that it's only the company has money. I can't watch television if I can't pay. I have to pay the telephone cellular to call here and there it ultimately take all the money.

### **Mismatch Between Patients and Physician Illness Model**

**Latino illness model.** The Latino participants believed that, rather than investigating their illnesses more deeply, doctors in US hospitals simply prescribed medications or surgery. In addition, most Latinos believed that medications were not a long-term solution for undiagnosed abdominal pain. The participants judged the quality of their doctor's care by the lack of trust in doctors and the severity of their' unrelieved, and untreated GI illness symptoms.

(S3) What type of relationship? Nothing, I go in and tell them I want to know if the exam results are in. You haven't called me and they said, we don't have to call you. You have to make an appointment to see the doctor. No relationship with the nurse. Because before if something comes up the nurse is the one that has to call.

(S5) Yes! Yes [lack trust] because one [doctor] said this one [surgery]) is better and the other one said this one [medicine] is better. I don't want the risk! Yes, the risk is much greater than coping with the symptoms!

Most participants expressed the belief that if their physician would only listen carefully to their history and current symptoms then a proper diagnosis and solution could be reached. Although their belief in the process of care was perhaps not well founded (since GI illness is complex to diagnose), their belief that such a simple intervention would cure likely added to their frustration with care.

(S12) I would think so because if they listen to all of your symptoms to all that has brought about the stomach problem the doctors have more information and they well know more about your problem that you have and thereby give you a proper treatment. Yes, if they

listen to all of the symptoms and everything that is related to the stomach problem you are able to reach a diagnosis.

(S12) They [doctors in Mexico] listen to your symptoms and all it's related to but it is not all the doctors there are some doctors that give you the medicine you need and a lot of times you don't have to go back for the same problem.

One consequence of the Latino participants' inability to establish relationships with their doctors was that they did not trust their doctors. This lack of trust influenced the participants' perception of the treatment option(s) recommended by their doctors and the participants' inclination to accept or reject various options. Specifically, many of the participants assumed that the safest GI illness care option was the option that was least invasive.

(S1) Oh, pills first. Because the pills are less (invasive), so they help to take away the pain that is better [safer] the pills. But if they the pills don't help that well, the operation! But the operations are painful and hard and we will need to put rest [time off work with no pay]. Yes, if the medicine does not work yes, I want the surgery! Yes, the operation. Yes, if the pills don't work. But it's not the first option. I want medicine. I will say no to the operation. Because the operation yes it will take away the pain fast but if there is a form of medication well better the medication because the operation takes time because you have to rest it may leave you sicker, I don't know!

The participant felt that his care was so inadequate in the United States that he considered giving up his family's costly 15-year-old pending applications for United States citizenship to risk crossing the border illegally back to Mexico to get cured. Many Latinos believed that they could be cured by doctors in Mexico because these doctors spoke Spanish and shared the participant's cultural health care beliefs.

(S4) If I could go back to Mexico I would go seek treatment over there I would get cured.

Because the doctors over there are the same race. It's true that you have to pay [in Mexico] because you have to pay. But they. It's the same culture, the same language. You, feel more comfortable you can speak the same language the, the same race the same culture.

This participant recognizes that he is more comfortable with the model of medical care practiced in Mexico. Elements of care that he feel are lacking in the relationship with his US doctor are the personal attention, personal relationship and effective communication that he experienced in medical care in Mexico. He also is pointing to the lack of an ineffable comfort that comes from sharing a "race", "culture" and language with his provider. Lastly, a personal relationship with doctors serves as the basis for participants to develop trust in their doctors.

(S3) I feel no confidence as if talking with the doctor that is treating me so she could understand me. Is not the same to have the nurse translate [for] me instead of me talking personally with the doctors.

(S1) Yes, because we would speak the same language and the doctor would understand me better. Because I could explain what is happening in my own words and they would be able to pay better attention to the patient. Instead of just giving you a piece of paper and send you on your way. They could instead give a better explanation in detail.

**Fear of Being Reprimanded for Holistic Treatment.** Most Latinos interviewed did not believe that strong medications such as morphine were appropriate treatment for their GI pain. Instead, Latinos believed that doctors could cure their GI illness without such medicines. Regardless of whether this belief was founded in reality, it was frequently expressed. Some participants believed if the doctors understood the root cause of the participants' pain, doctors could cure it. Several participants were convinced that doctors would not accept Latino health care beliefs and

practices as a valid and safe way to treat illnesses. Participants were certain that doctors would blame them for being sick if they choose to heal their bodies using cultural health care practices.

Participants felt that their doctors believed Latinos immigrants lacked the necessary knowledge about illnesses and treatment modalities before they arrived to the United States. However, participants and their families clearly communicated their use of cultural health care practices to manage GI illness and restore their health.

S12 No, no! I have been prescribed pills and more pills and no I have not felt they are helping. But, then there is tongue lash that, you are not well because you don't take them! Doctors are good at saying "you are not doing your part that's why you are not doing well."

(S5) I think that it's negative because if I tell them [doctors] and something bad happens they will and say you should have not taken this! Why do you take this?! I don't think it was that.

Latinos in this study accepted and honored their cultural health care practices. Therefore participants took herbal medicines for GI illness because it felt very natural and was inexpensive, effective and easy to do as their primary health care for digestive complaints (Brett White, Knox, Zepeda, Dennis, and Felix Nunez, 2009). Participants feel that providers should be cognizant that Latinos immigrants' cultural health care practices (herbs) are often used as their primary health care while US health care is often utilized with the belief that Latinos may be harmed.

(S5) Because, I take it into account and well it is the same the same. If I tell or don't tell for me for me this is the point I see. They don't understand that we Latinos have been doing these taking herbs for a long time.

(S5) I take this because my mother and mother in law are better persons and they know the natural remedies. So many times we are the things that the doctor gives us (medication can cause illness). I tell you if I use things that are natural I will not get sicker than I am already. This is what I believe. Oh no, I don't tell the doctor! I think many times I don't tell them out of embarrassment because, because many times I find that many of these doctors don't know about things that are natural. They don't understand the things that are natural that we [Latinos] use.

(S5) Then I think if I tell the doctor and they don't know the natural things they are going to get upset! This is why I don't tell them and this is why I don't tell them many times this is part of my culture, yes?

Latinos said they felt powerless, insignificant, and unable to get their doctors to take interest in their health care. Consequently, some Latinas transferred their care to a new doctor and clinics only to receive more disjointed GI illness health care. Other Latinos believed care ended when they left the clinic or ED. Lastly, participants described feeling trapped in their sick bodies due to the lack of appropriate treatment for abdominal pain.

(S5) Okay, well I want something deeper something that is directed to what is the problem! Investigate of why, why do I have the inflammation? You tell me what it is! Well, I think that first they should do the endoscopy. Because the first thing that they give me is pill. The pills all it does is calm the pain but it does not look deeper into the illness they don't know the exact diagnosis I have!

When participant speak of 'cure' it is possible that they are using the term in an idiosyncratic manner. It appears that they are asking or hoping for not so much a cure, such that



the illness is resolved. Rather, they seem to be using the term to mean adequate treatment, and management of symptoms.

(S7)I don't know what has caused this pain. The important treatment that I am waiting for is a medicine that I need this is important for me. Because it has been many years that I have abdominal pain and nothing to take it away right? Uncontrolled pain is a warning sign. The most important thing for me is to have my pain alleviated and taken away. "The things that makes me scared is cancer because a lot of people that I knew had cancer in there stomach and I though this is what I have for many years now.

(S6)I do not know, like us, we look for medicine and put it on [the problem] but in the stomach is not easy to find something to put on it, and cure it, because you cannot see it. We can have anything cancer or anything.

(S10) Bad, they have treated me it's that no they have not cured me. They have acted bad! That doctor what she did? And they charged me \$300 and something dollars and they did not do anything good to me. And before I did not have insurance and whatever little thing cost a lot. I went in at 5 pm and it was 3 in the morning and they still had not seen me at the hospital in the emergency room. So, I just left they didn't see me in time and then they charged me two hundred and fifty something dollars and did not even clear me to go home. And I had to pay the bill! They didn't do anything to me they told me what was wrong with me is that I have an ulcer and to see my doctor for further treatment. And I had nothing more to do with them other than to pay the bill.

The significance of being treated with respect and listened to were not considered niceties in the healing process. Rather, many participants believed that the entire orientation to care, that is, being shown respect and attention, could be curative.

(S1) Yes, yes if they [doctors] treated my problem differently and they were truly caring and would tell me the truth and showed more interest I would get better. I feel they focus more on the problem than the solution. They have the knowledge, the doctors, of health and the medicines. Why then don't they give medication that will help? Instead of seeing me all the time all the time. They should cure me and make this [GI illness] go away.

Distrust in the physician even extends to the point of believing that s/he has treatments that might be helpful but are being purposefully withheld from participants.

**Mismatched illness models.** Not only did Latinos receive GI illness care via inaccurate translation, but the care they received followed a western biomedical model of care that was unfamiliar and poorly accepted. Latinos believed that their doctors were quick to prescribe medications instead of investigating Latinos GI illness concerns. The mismatch in illness models between participants and their physicians left them feeling confused, and unaided by their doctors.

(S5) Well, because the doctor is American and didn't speak a lot of Spanish and I don't speak any English, and that is the reason that I didn't understand what I had, and I assumed it was an infection because they gave antibiotics.

(S1) It makes me feel bad because they don't give explanations of what I have. They don't say anything all they say is your stomach is irritated. Your stomach is irritated the food you eat gives you this (crying).

(S3) In a moment I think that I do not have anything. I had been told that is only stress or nervousness but it's not because I cannot work. Because, I cannot stand my stomach how could it be stress or nervous? Here in my work I should not be feeling like this at least at home. Well, I could feel like this but the pain is always bothering me.

(S12) Well, here, you go and you are asked: what is your major problem and that becomes their major emphasis. In Mexico, no, you tell them your major problem and everything that is related to that problem. So they give you to treat your stomach and along with that they give for all else that came [treat the whole person]. Well, yes, it's good for the patient because you go for a health problem and you disgorge "*desahogar*" or let it all out, other problems that were brought about and the doctor not only treats your stomach but also the rest of your problems. I would think so because if they [doctors in Mexico] listen to all of your symptoms to all that has brought about the stomach problem the doctors have more information and they will know more about your problem that you have, and thereby give you a proper treatment.

Participants entered U.S. healthcare with expectations for care that were formulated during their health encounters in Mexico. Key revelations encountered in care of their abdominal pain in the US were the lack of a personal relationship with their health care provider, covered earlier in this chapter, symptom treatment, primarily via prescribed medication, and a focused, rather than thorough or holistic assessment of their health and wellbeing. They struggled with the lack of thorough assessment and felt that physicians were doing minimal assessment, depersonalized assessment and sometimes no assessment, as in the patient quoted earlier who was handed a prescription as the physician entered the exam room. Additionally, they felt that the diagnosis often missed the mark. Being told that their abdominal pain was a result of "stress and

nervousness” was not helpful when the pain was so severe that it required them to miss work. And finally, the focused attention to the presenting complaint, to the exclusion of other complaints, was considered incomplete care. Participants believed all their complaints to be legitimate, and likely interrelated; they were accustomed to presenting the big picture to physicians, and that action was believed to contribute to healing. In contrast, focused, quick, depersonalized, allopathic medicine felt lacking and incomplete.

One participant with no previous experience with the United States health care facilities described his experiences when he sought care for GI illness. The participant was unable to understand how the food he ate every day was now making him severely ill. Also, he did not know how the medication his doctor prescribed would cure his abdominal pain.

(S6) No, I did not have an interpreter, nothing. Well, I was told that I need to see a doctor and I was given a prescription to go buy it and this is what you are going to use. With time you are going to be fine the doctor (said) in Spanish.

I did not know how to explain because I did not ever get sick before. Like the doctors did some studies and told me to only eat food that did not made me sick like vegetable and fruits and not to eat food that make me sick.

Furthermore, participants felt their doctor’s health care recommendations were not something that Latinos generally implement to improve their health or have access to (i.e., swimming pool).

(S12) No, no because they have always said: “take the medicine, and we recommend you exercise more.” What is more she even recommended that I swim. I don’t know why, maybe it’s because of the stress. I don’t know. I don’t know, but I have done all this and

the pain here doesn't go away. I try to eat healthy foods, like vegetables, fruits. I use to drink sodas and I stopped that. I take walks.

Participants believed that doctors did not inquire about their illness concerns although it was the doctors' professional responsibility to do so. Furthermore, if doctors communicated better with the Latinos, the doctors would have a better idea about their patients' illness experiences and concerns. Language barriers and the ineffective use of non-professional interpreters left participants unable tell their illness story and fearing they would never get well again.

(S5) I don't know maybe that is why I didn't ask because when you're at the clinic they are always in a rush and busy and maybe that is why it's hard to ask questions. Well, I think the only opportunity you get is when they doctor asks how you feel. Why do you have this? And why did you come? I think those are just routine questions just routine and we are limited to answer that!

(S12) I don't know that they would spend more time to find the cause of the problems that one has come with. If nothing more to listen to listen because to many times they cut you off in the middle they will not allow you to say everything, everything. They don't hear what you are saying so in reality it is the same treatment, right? After, I say in reality they are not caring for me or my pain.

(S8) If I were to speak to my doctor he wouldn't tell me because you can see that the doctor is just there not listening, and not making any decisions. And you remain in the same condition they don't give you options. For one reason or another they don't say

much. You can, but I haven't because I never have the time. I have so little time with my doctor don't have time to ask all the questions.

(S9) Well the communication is very short because there is very little time. I really do not know why. In that aspect we wish we had the time and tell the doctor everything we are feeling but if we see them rushed and with very little time. Then you say well I couldn't tell him oh well I wasn't able to let him know. Because I always say maybe next time I can actually talk long enough with my doctor. I think if we had a little more time so we can really communicate and explain to the doctor what is going on because the doctor does not know what is going on with me.

Participants described a vicious cycle of ineffective communication with doctors, disjointed care and not enough time with their doctors that resulted in Latinos' being confused about what caused their abdominal pain and how to cure or manage their illness symptoms.

(S5) I was not well informed. No, they didn't tell me the cause of that pain no, they didn't tell me. No, no they didn't ask me and I didn't ask either. No, they didn't ask me those types of questions because my stomach was swollen.

Besides the confusion over how the medical visit should be conducted, participants repeatedly were exposed to the barrier that language presented. They were acutely aware of the negative impact that language barriers had on their ability to access care, comprehend the doctors' illness explanation and lastly, convince doctors to pay attention to their suffering. For example, doctors relied heavily on interpreters to both interpret and explain medical information to Latinos. However, Latinos believed that doctors did not utilize interpreters effectively because doctors did not ask the Latino about their illness concerns. Latinos witnessed that when English was spoken by other patients, doctors felt obligated to pay attention to their English-speaking

patients. Participants understood the significance of reporting symptoms of GI illness directly to their doctors. In fact, a large body of research supports that doctors must communicate with their patient obtain a detailed history of their abdominal pain if they expect to diagnosis and treat abdominal pain in a timely and safe manner (Lacy & De Lee, 2005).

(S1) When you do have someone [interpreter] help you they are not telling the doctor everything you are saying to them. The doctor says a lot of things, but the interpreter says only a little bit. Or the opposite happens where the interpreter says a lot of things and when the doctor said little. There are words that are said to me that I don't understand. Nothing is said to me specifically just words like it's your acid your liver or it's your intestines. But no explanation as to what is specifically wrong with me.

(S7) Ah bad for me is that I don't know how to speak in English. I do not understand English so I can't communicate with them. This is bad, this is bad for me because I am not able. If I can't speak English I can't talk to my doctor not able to do work well when I am presented with an opportunity [to communicate] then it goes away! I am not able to get the communication [directly with doctors]. It affects one [a person] because like I told you, I can't well, my mind won't help me, right? I am not sure for these years I have had this I am not sure why? Like this I feel frustrated right! Well, I am not able in reality to communicate with them (*Child crying hard to hear*). Well, I am not able to talk. I want to say a lot of things but I am not able talk or communicate with them [doctors].

(S12) They always speak in English and they usually have somebody translating. It's someone that also checking the blood pressure [medical assistance]. No, a lot of times what happens the person who is translating says that I feel this or that and there is times

that they don't pass on all the information. Well you would say wait this and that hurts, wait until I am finished, and they don't do it! Well, that's the problem that's where the patient is at fault by not saying anything. You just keep repeating the same thing and it doesn't get translated. Well, I don't know how to explain it. It's just that I don't know how to explain it. It may be just letting it go you just remain silent.

Participants were aware that time and attention were essential components required to communicate GI illness across language and cultural barriers. Consequently, the doctors' time constraints created enormous barriers to participants' effectively communicating their illness story.

Naturally, native-Spanish-speaking Latinos speak their native language without much thought. Only when Latinos entered the United States healthcare setting did they feel a break in their capacity to use Spanish to communicate. Latinos felt doctors attended poorly or ignored them and this created a barrier to communicating their illness concerns. English fluency translated into quality attention from doctors in their clinic observations. They witnessed doctors paying attention to non-Spanish speaking patients and realized that the Spanish language was not valued in the clinic. Conversely, Latinos observed that English language was highly appreciated, respected, and preferred by their English speaking doctors because time constraints were common place.

(S1) It's just translated. Well, I am not happy. I am not satisfied because I don't understand. I don't feel I'm being told what it is the truth. I'm not told. I can't speak. I feel bad because I can't speak to them (doctors) in Spanish. So that I can explain to them personally explain, what is happening to me. Yes even with the interpreter, this is how I have felt. They just say a few words or direct me to say yes or no very specific to the



questions being asked to me. I want to say more but they won't let me well, I want to explain more things but they do not let me.

Latinos believed that when patients spoke English, doctors felt obligated to pay attention. Latinos concluded that only when English language is spoken will the doctors know the patient and their illness concerns. Lack of attention and poor interpretation contributed to partial and inconsistent care.

(S7) They say you don't speak English, right. They're more interested in those people, I think! Those, doctors also speak more words than I hear and I understand right?

The possibility of an English speaking doctor paying "attention" to Latinos was greatly reduced or was nonexistent as described in the text. Latinos developed a negative assessment of their health because of their doctor's inattentiveness to their illness concerns. The solution, one participant believed was a trusted interpreter who would take her Spanish words and convert them verbatim into English words so that the doctor would know her personally. She felt that her doctors should have been transparent about what they could and could not help her with. Additionally she felt that doctors should have stopped focusing on the problem and focus their skills and attention on discovering a solution or cure for her GI illness.

(S1) Well, I would have my own interpreter someone I could trust and have a doctor that would understand me.

Participants who felt abandoned and left to suffer with GI illness for years implemented various cultural practices to cope with their GI illness.

### **Coping with Barriers to GI Illness: Cultural Beliefs and Practices**

In summary, factors that matter to Latinos in communicating their GI illness concerns included trust, time, and attention, and respect, consistent follow up care, and doctors who

showed concern. Participants' coping processes included following their US doctors medical advice and prescriptions, as well as reliance on folk medicine, God, and family. Despite using these coping strategies, Latinos experienced considerable untreated pain, delayed or ineffective diagnostic work-ups, and lack of access to diagnostic tests (i.e., esophagogastroduodenoscopy).

One consistent response from participants was to give up hope that their doctor could effectively treat their GI illness. Over time, participants lost heart and no longer pursued treatment in the US health care facilities. They, like the woman below, reasoned that if they were not going to receive help, why go?

(S7) The experiences that I had is that the stomach pain they gave me one medicine but it did not take it away [the pain] but helped me a little. It [pain] went down a little helped me but did not get rid of the pain. I was thinking that there is not a medicine to stop the pain all the time right? I will not go back. This is my question and my experience is the same why go back if they cannot help me they don't give me medicine that will help. If that can't help me why go?

(S7) Now, I just canceled the other appointment! They called with another appointment but I think I don't go. Because (loud ringing noise) no one is helping me it's the same. I don't go that's enough!

One participant believed that people lose their ability to cope when being given substandard care. The participant coped with feeling mistreated by his doctors by refusing to communicate with them and distancing himself with anger.

(S10) Well that is why some people go crazy and kill their doctors. It is better to get to angry (but stay away).

When treatment in the clinic proved unsatisfactory, some Latinos sought alternative sources of cure.

(S5) One has to go to things that are natural because no, no there are no other things and that's when one goes into the natural. One goes to the remedies that are natural. After this happened, this situation happened, I went to go see a naturalist to get treatments that were natural. Yes, yes. Yes, it true I used all of these things because I don't have, I have not been told exactly of my diagnosis. Yes, yes. Yes I am investigating this yes and this is like a coping.

(S9) So, I got frustrated and I just gave up and started drinking the ranitidine (Zantac) because that helped me a bit. Very sad. Well, I started crying because yes you cry when you can't find the help for your pain and you have to cry to let out what your feelings.

After numerous disappointing attempts to get their doctors to provide a treatment option to manage their GI symptoms participants, were physically and emotionally exhausted. Participants described feeling depressed every time they tried and failed to obtain care. Yet, they didn't give in to their sorrow or fear of dying. Instead they used culturally familiar beliefs and practices to cope.

(S1) No, I am trying to survive and live with the pain! The treatment I don't think there's one. Yes, I have to cope. There is no one to say what I have I think there is no solution to my pain! Well medicine, medicine and I don't feel better or good. I can't find a solution I don't know what to do. That's why I have to cope, raise myself up. I think it might be [cancer] but how will I find out? I don't have a good insurance medical or none of that so can't go get more help! Yes, I have to cope with it!

In coping with inadequate health care most participants went back to their cultural health care illness beliefs and perspectives. Many participants turned to their family and community members for answers to their GI illness concerns. Participants trusted the health care solutions provided to them by their families. They felt comfortable with the diagnosis and treatment options that their families provided.

(S5) Well, from my mother and my sister-in-law Yes! No! Well, yes my mother told me she said that when it's your kidneys and my sister-in-law that it's a lot of times your kidneys she told me when its blood it means that you have a very strong infection. Yes, I believe what my sister-in-law says.

(S7) Yes, I called my mother and she told me about it. This is how information is passed on. This is good for your stomach. It's a half a glass with lemon with a purple onion. No, raw [onion] along with parsley and garlic then you blend it. You then put it in the refrigerator and drink off of it every day for nine days. This help your stomach and to clean the arteries. I just started about a month ago. They say that if you eat a lot of grease just take a couple of spoonful.

Folk medicine, home remedies and self-prescribed food restrictions were employed to address GI concerns. As well, culturally trusted treatment providers like naturopaths or herbalist were used.

(S5) I personally took it upon myself to leave caffeine from sodas, coffee the teas none of that. I limit myself to milk and water in the mornings I think this will help me. And home remedies that my mother in law has made me like the horse tail tea "*cola de cabballo*"

and corn silk tea “*pelo de elote*” things like that for the kidneys. Because I think that is what I have, a problem with the kidneys!

(S6) When I was around 14 years old I had them [worms]. A lot of Mexican persons had them. There is a tree in Mexico that has them. There is a lot of yams that you could use. When I was around 8 or 14 years old I used to eat them [yams] to get better there are a lot of natural [remedies]. If you have pain you eat [yams].

Several participants sought care from natural or alternative healers (i.e., Chinese herbalist, PhD, community member). Although many Latinos use natural medicine to treat their GI illness pain they discovered that natural healers in the US are not the same as the ones in Mexico (i.e. Curandero). For example, in the Mexico naturopathic treatments generally consisted of small amounts of hand harvested herbs and teas as well as the use of prayer, candle lighting, and massage. Natural healers are a significant part of the Latinos cultural practices. Consequently, participants found natural healers in the United States helpful because they provided the participants’ with knowledge about their abdominal pain that was consistent with their cultural beliefs and practices.

(S5) Well, I am convinced that yes [naturopath] she helped me with the medication that she gave me I felt, I felt real good! And time has passed let me think how much time, four years. I was forty years old when this happened to me. Then after four years it [abdominal pain] came back that I had an infection. But yes she told me put, she recommended a cleansing “*limpia*” [for] my stomach two times a year minimal to take out, all the toxins. No, she has she has ah she has courses of training with doctors these doctors are not from the same type of medicine [conventional]. These are doctors that have gone to have natural training qualifications. No, here in the United States. Yes! Well because this lady who has

the natural products she does the reading of the eyes, iridology. That's when she saw all of this and she told me my biggest problem or preoccupation of the body the biggest one is that I'm very young and the numbers of my kidneys are very low.

Several Latinos in this study continued to honor their cultural health care beliefs while at the same time seeing US doctors. In this study, US treatments failed and participants returned to their cultural beliefs and practices which generated faith that one day they could be cured and their health restored.

(S6) Also, the doctors ask questions why I got sick I do not understand him. At the time that we are born we eat a lot of food meat, flour, chilies and bread at the time that we eat it gives us energy but with time it gets our stomach dirty and this is what it gets us sick. We as Mexican we get sicker because we eat everything. A natural doctors says that it is from the food that we each, meat, coffee and because we do not clean our intestines. We only clean outside of our body but we do not clean inside.

(S6) I have told them [doctors] that it was better the Mexican doctor because a Mexican eats the same food. American does not understand because they don't eat like us. In Sequoia medical clinic I was told not to eat meat, milk or anything only medicine. I had natural medicine from Amway product (showing probiotic) and I got better and now I eat meat, chicken, beef and everything.

(S7) No, they did not tell me but I know. I know it was the food that was not good! It was a chicken that was bad! I ate the food and my stomach was feeling bad. I was not able to eat I had a lot of "asco"? I was not able to eat. Time passed that I had pain and pain. The doctor told me this is gastritis that you have gastritis, colitis all that, but no one gave me

any medicine to alleviate it. Always with the pain to date now for 20 yrs. There are times when I eat things that are not good or eat outside my home I will always get diarrhea, always! If something is not real clean or the meat is not clean I always get pain and diarrhea pain.

### **Trust in God and family**

One health belief shared by all participants was the fear that their symptoms indicated cancer. To cope with the inability to communicate with their doctors and get a clear diagnosis for their GI illness the participant's accessed family based coping coupled with their belief and trust in God.

(S3) Well in moments I think I do not know. It gets in my head like cancer is spread because my father died due to cancer. I ask myself "do I have cancer?" And I put this in my mind. I get sad because I think about my son that if something happens to me I am going to leave him by himself. Is my mother [going to raise him]?

(S3)What else could I do but go back home the same way. Well yes, there is no other way. And see tomorrow how I wake up. I tell my son that I ask God that tomorrow I could be able to go to work. These is [are] the things that I ask God to give strength to be able to work because the bills get home. Well yes, it is true with a lot of effort, because sometimes I had gone to work with a lot of pain that it has been difficult for me, to drive because I [am] sitting down and the pain in my stomach is very strong. I had gone to work with a lot of effort. I just get to work and get off the car, and enter to my place of work. It is sad and I asked God to take away this pain. I do not have any other choice but it is hard.

(S4) I would just put myself into the hand of God and the Virgin [Mary] and to go on with life until I could no longer “aguantar” [take it like a man, don’t cry, and don’t complain]. Running away was not an option.

(S8) Praying a lot to God asking God for everything. Having my mind in God because God decides what is to be done. If God decides to reconstruct all of my stomach everything will be perfectly fine. I always stop to think if God gave sight to the blind, if God healed the cripple why he wouldn’t do it on me. He will also if he wants heal my mind and heart if he so wants. Like the priest said the other day Father Alex “If you are healthy from here [mind] and here [heart] everything is healthy.” But if you are always complaining oh how sick I am this hurts me and that hurts me.

**Monitoring food-related symptoms.** Many participants, in trying to manage their own GI symptoms, closely monitored foods that were and were not related to an increase in pain or GI distress. Some participants seemed to be able to identify those foods that were most likely to cause irritation and pain and avoid them. But others found that they could tolerate only a very limited diet. Here again, the lack of adequate guidance and treatment from US health care providers left Latinos with few options for comfortably managing their symptoms.

(S5) Ah, no I think I noticed that when my stomach inflames for example with the beans at times. Yes, with food with certain foods I feel like it’s inflamed for example if I eat potatoes, cabbage. Ah ha with these types of foods that I get it like broccoli inflames me! No, I’m a regular just once in a while I get inflamed I think also when I have stress that’s when my stomach inflames. I suffer times I suffer constipation when I eat don’t eat fruit and many vegetable or I eat sardines I get a lot of constipation with the sardines!



(S3) For me for this pain they only gave medicine to help me with the food I eat but it did not help. I cannot eat anything, anything, everything that I eat right away I feel sick, I cannot drink milk, cheese, cream, meat, nothing, nothing, I can only eat beans or things like that, nothing spicy because I feel like if my stomach is burning and it hurts a lot.

(S1) I think daily and plan my food so that I don't get pain. So I don't feel it. Other things to stop the pain is I drink water or drink milk. Yes, but soymilk the other (cow's milk) provokes me. Yes or I eat. Because I drink water I always drink water. I don't drink soda all the water but when I have this pain (pointing to the abdomen) I run to get soda water, I drink a little bit at a time and he gets rid of it! Yes, when I eat foods that make me sick. Yes, foods that have acid have lots of fat the breads, the soda, and the coffee.

(S8) Everything, everything gives me a heartburn everything is harmful to me! Say for example, I am going to make enchiladas, I will not add much chili to them. I'll put just a little and I will not use any type of grease. Say, I am going to make menudo.

Yes, *menudo* is part of our culture. We [Latinos] are all used to eating *menudo*. So when you crave it, you will have a small portion and with little chili. Because you know it will harm you so I am cutting back. Look this is worth noting. I used to make menudo once a month and now I'll say, this is good and my husband goes along with it. My stomach doesn't tolerate it much and neither does my husband. I will have a small portion every now and then. It's about a half of what I used to have. I don't have as often as I used to both in frequency and in quantity.

**Adjusting clothing to avoid abdominal pressure.** Several participants discovered ways to lessen or manage their GI illness symptoms. For instance, several participants discovered that

clothing worsened their GI pain; to cope with this pain, the participants tried to adjust their wardrobe to diminish pain.

Several participants believed that if their clothing touched their abdomen it aggravated their GI illness symptoms and worsened their abdominal pain. For example, several participants discovered that adjusting their clothing away from contact with their skin was a way to decrease GI illness symptoms. Participant describe below how they discovered ways to manage their GI illness at home.

(S5) This will go away for example when I'm working the whole day on my feet. At times the clothing feels very tight. When I come home to the house I unfasten my pants and I leave my body like just natural so that I don't have anything putting pressure. And I feel more relaxed and after a while its takes it away. Not always, but I notice it mostly in the evening it happens when I been out in the day. About six or seven in the evening that I work. Like something kind of a little bit tightening and around my stomach. And my husband he says look at your stomach it's inflamed.

(S1) I cope with this [abdominal pain] by putting my clothing like this (clothing rolled up away from her stomach).

(S1) It is a routine that I deal with all of the days! All of my days a routine! I look for the pants that I can wear that are not tight on my stomach so it doesn't bother me. And blouses that are not really tight I buy the blouse loose. I plan day by day so that I avoid things that affect me. First, so that I don't get preoccupied I plan my next day.

**Adjusting sleep position to avoid abdominal pressure.** To cope with GI illness symptoms several participants had to adjust the way they slept.

(S7) But I have pain in the night so I lay like this with my face down on this side [right]. I sleep like this because it hurts (left side) this side.

S12 No, I try to sleep but I just look at the ceiling. I am only able to sleep with my mouth facing upward. Yes, mouth downward, I cannot do that. Yes, when the pain is real strong it is harder more work for me to get to sleep.

S1 Yes, and I lay with my mouth facing down!

### **Getting around Access Barriers**

**Coping with no attention-communication.** In summary, Latinos tried to negotiate a better situation with their English's speaking doctors by using an interpreter but found the interpreters services, grossly inconsistent with the need to communicate illness symptoms with their doctors. To cope with communication and access barriers some participants sought the help of a neighbor. Two examples of how participants coped with barriers to care are presented here. The first participant describes how she coped with barriers to care while experiencing severe abdominal pain. She took a narcotic medication given to her by a neighbor. The second participant describes how he coped with barriers to care. He took an unknown strong medication given to him by a neighbor which masked, pain from a serious GI illness that would later required him to have abdominal surgery.

(S5) She [neighbor] had the same experience as I did [abdominal pain]. So, I believed her and when Macias [neighbor] came to bring the pill [narcotic]. I took a pill [narcotic] for the pain without any prescription. I don't know the name of the medicine but if I am not mistaken its Vicodin or something like that. My neighbor [Macias] gave it to me. And she said, I don't have that pill but I can get it for you and she did! And when I took it [Vicodin]

I started sweating and sweating, and sweating and the pain went away. She told me if you go to the emergency there not going to do anything and you'll get this big bill. And that's all there going to give you is this pill [narcotic]. So I said ok. I don't like taking strong pills because I don't have them. But that day I was crying so much because of the pain I took it!

(S4) I got a pain that was not normal pain [not like] that I had all the time. It almost made me fall over it was bad so strong. I had to call a lady that lives on the street to help me and she said "I will go get you something" not sure, what she got me but it helped. Worked for about two hours and in the morning, it was the same (severe abdominal pain). I was getting ready for work. But no, the pain came back the same and it was very intense! So, I went to the hospital. I was there all day Sunday and until the night. They called me and told me I was going to another floor because they were going to do surgery (gallbladder surgery) on me.

### **Summary**

In this chapter I reviewed the stories and reflections of the non-documented Latinos with abdominal pain. The strongest theme in their narratives was that of the disrespect and invisibility of their suffering when they sought care in the United States health care clinics. Another central theme was their inability to effectively communicate illness concerns to a provider. In their narratives Latinos reflected on how language barriers impacted their ability to establish rapport, and trust in their doctors. Another significant theme was that of Latinos feeling singled out by health care staff and discriminated against based on ethnicity, language, lack of insurance, and the lack of documentation.

Clearly expressed in the Latinos narratives was that of the receipt of delayed, inadequate, and unsafe care. Another common theme was their inability to receive adequate follow up care

for GI illness. Another noteworthy theme was that, of the mismatch between Latinos illness beliefs and the physician illness model. Many Latinos voiced fear of being reprimanded by providers for the use of holistic treatments. Finally, their stories revealed the significance of cultural beliefs and practices when coping with barriers to GI illness.

## Chapter 5

In this chapter I discuss the significance of the findings. Unique knowledge about the health experiences of NES/LEP Latinos that were discovered in this research is summarized. Clarification or extension of the symptom management model, based on the findings from this dissertation, are suggested. As well, the implications for practice education and research are offered.

### **Significance of the Findings**

Despite the philosophy of patient centered care, and despite the health care regulations that suggest that care be delivered in a culturally appropriate way, and in a language that matches the patient's preferred language, Latinos received culturally and linguistically inappropriate health care. Health care initiatives call for providers to deliver care that respects the person's culture and language. However, in this study Latino patients tell stories of being disrespected in the health care centers, and unable to communicate illness concerns with a provider. Often this population set aside deep seated health care beliefs to receive care via the biomedical model because the model significantly differed from the populations' health care in Mexico.

Latinos discovered that communicating their health care beliefs and practices within the constraints of a biomedical model left providers uninformed of the population's expectations to be cured or have adequate management of their symptom(s) without strong medicine. Furthermore, the biomedical model lacked a stable linguistic and cultural care component (i.e., professional interpreter). For example, the model is used to provide care to all patients in the US regardless of their language and culture differences. Hence, using a complex medical model to care for LEP/NES Latino patients resulted in linguistically and culturally inappropriate care in this population.

The findings revealed that Latinos could not convey to their providers what types of care they preferred even with the use of an ad hoc interpreter. For instance, Latinos were not able to describe to their physicians how that they expected to be doctored (i.e., cured) or alleviated of their illness symptoms. The study further uncovered how Latinos could not comprehend why, after multiple visits to the health care center, their doctors did not provide a cure for their illness or inform this population how to lessen their illness symptom(s).

Latino patients clearly expected holistic care from their US doctors that never materialized. Instead, the findings show that their doctors did not integrate Latinos illness beliefs into their health care delivery. For example, Latino patients believed one sickness (i.e., abdominal pain) could have many causes and various symptoms. Therefore, they expected doctors to investigate the whole body. When they did not, Latinos felt diminished rather than cared for or cured by the care they received. Finally, the participants produced countless stories of being unable to develop a relationship with their provider, something they viewed to be an essential element in their model of healing. An inability to establish a strong patient- provider relationship left Latinos wondering who was accountable for their care. In fact, the study found that in a single health care visit various providers, both licensed and unlicensed, made contact with Latino patients, always across language barriers, leaving them feeling that their care was fragmented.

Often Latino patient's health care was delivered in such an uncaring way that patients felt they couldn't get better. In fact, Latinos reported being harmed while receiving care. However, it must kept in mind that Latinos accounts of being harmed by doctors were linked to their beliefs that doctors refused to cure their illness based on language and ethnicity differences. Finally, Latinos felt discriminated against by the acculturated unlicensed Latino health care staff in the health care centers.

In their stories Latinos felt their doctors perpetuated a cycle of ineffective and fragmented care. They believed that by not listening to patients' concerns, not providing sufficient feedback within the encounter and not providing follow up care doctors were insufficiently engaged. Furthermore, participants expressed frustrations and lack of trust for providers who deliver linguistically and culturally inappropriate health care.

The findings revealed a population of Latino patients who felt unsafe in the health care centers and therefore avoided advocating for appropriate care and treatment options. In fact, Latinos patients believed if they advocated for better care they would upset the health care staff and possibly risk deportation.

The biomedical model was unfamiliar and poorly accepted by Latino patients in this study. Therefore, providing appropriate care to this population requires that provider, and health care centers have a clear understanding of the meaning of culture as it relates to this population's illness experience. Finally, linguistically and culturally appropriate health care include appropriate symptom management for all patients. Below, I will briefly clarify the symptom management model based on the findings of this dissertation.

### **Clarification of the Symptom Management Model**

The processes of symptom management are positioned within the *dimensions of nursing science* located in the theory of symptom management (TSM; Humphreys, 2008; Linder, 2010). These domains include *person, health and illness*, and the *environment* (pp.670-671). Within the TSM, the term *environmental domain* refers to the context in which symptoms are experienced. Environmental domains include beliefs, values, and practices that are unique to various ethnic groups and religions (Dodd et al., 2001). The symptom management strategies include directive questions designed to reveal important background information that informs intervention



strategies (Dodd et al., 2001; Humphreys et al., 2008; Linder, 2001). Finally, the central strengths of TSM lie in its ability to serve as a conceptual framework that explains how individuals and families experience symptoms and how symptoms are managed both by patient and by providers (Humphreys et al., 2008).

A key finding in this study was the mismatch between the providers' biomedical model and the Latino patients' cultural illness model. This mismatch resulted in linguistically and culturally inappropriate health care for this population. For example, language and cultural barriers resulted in participant's lack of symptom management strategies. Symptom management strategies refer to interventions implemented by the provider or patient in attempts to abate or lessen negative experience that symptoms may cause by way of "biomedical professional and self care" (Dodd et al., 2001, p.673). The findings of this study call for a deeper look into how the TSM helps us to evaluate and conceptualize Latinos' symptom experience, symptom management, and symptom status outcome, in the presence of profound health care barriers (i.e., non-documentation). This is an important point because this study found Latinos suffered illness symptoms for some time after multiple encounters with their providers.

The findings further show that Latino patients' health experiences comprised constraints versus capabilities, which interrelated with time, and changes in symptom expression. The TSM domains provide significant background information that can influence the patients' symptom experience, management strategies and health outcome (Humphreys, 2008, p. 149). Hence, the theory could be expanded to show how this population's *constraints* and *capabilities* impact *symptoms experience*, *symptoms management strategies*, and *symptoms status outcomes* (Dodd, 2001; Humphreys, 2008). Below, I describe how key findings of the study might be used to

expand or clarify domains within the TSM to show constraints and capabilities that impact this population's illness symptom experiences, and management of illness symptoms.

Latino patients in this study reported the inability to communicate their illness symptoms or received symptom management strategies from a provider due to profound constraints (language and cultural barriers). Furthermore, when this population sought care for illness symptoms they experienced constraints and capabilities. This is an important point because most Latinos due to their non-documented status remained in the *constraint phase* until they could access capabilities (i.e., community member support). The findings show that Latino immigrants experienced constraints lasting months to years in which their symptoms of abdominal pain were unmanageable, changed or worsened. During the *constraint phase* Latinos lacked symptom management strategies. Here it is important to point out that the TSM recognizes that the various management strategies can be implemented with individuals, family, or community; an example of a symptom management strategy is "self-care" (Dodd et al., 2001; Humphreys et al., 2008, p.; Jacobs et al., 2008). This is a salient point because this study revealed Latino patients in the *constraint phase* for a *time* experienced increased pain symptoms, feeling of hopelessness, and fear of dying. Consequently, Latinos initiated self-symptom management strategies (i.e., herbs, family support, God) as a way to cope.

Latinos eventually moved out of the *constraint phase* to a *coping phase*. In the *coping phase* Latinos evaluated their constraints and explored their capabilities (i.e., natural medicine, family remedies and support), to deal with multiple illness symptoms including pain.

TSM has been critiqued for lacking explanations or illustrations regarding relationships between multiple symptoms (Brant, Beck, & Miaskowski, 2009). In the same way, participants in this study suggest that care be delivered to the whole person. For example, treating the whole

person integrates all their symptoms, to include those arising from the emotional, physical, and or spiritual origin.

Finally, the socio-and cultural sub-section *environment* located within TSM could be expanded to illuminate the use of a biomedical model as part of the environment. For example, Latinos immigrants in this study were unable to consult or receive symptom management strategies or treatment via a Latino cultural health care model in US health care centers. The environment section of the TSM could be expanded to include immigrants, acculturation, family/community, and, the providers' use of the biomedical model with LEP/NES populations. Finally, with these additions, a TSM model may be more usefully applied as a conceptual framework to evaluate linguistically and culturally appropriate symptom management strategies in this population (Cardoso & Thompson, 2010; Jacobs et al., 2008).

### **Implications for Practice**

**Implications for providers.** Health care providers are in a unique position to promote linguistically and culturally appropriate health care for diverse patients. Creating an inclusive environment in health care requires a thoughtful and active commitment to a philosophy of inclusion and respect. Providers, as the professional leaders in most health care settings, can both set the tone and ensure that clinic environments and practices are broadly inclusive.

One way providers can promote an inclusive environment within a health care center is by being cognizant of the kinds of interactions that occur between non-professional staff and the NES/LEP Latino immigrant patients. Non-professional staff, including medical assistants, receptionists and technical staff are often the first contact patients have with a clinic. For a variety of reasons, including shared educational, language and/or cultural background, these staff may feel threatened by, or dismissive of Latino immigrant patients who seek care. Evaluating

staff-patient encounters for negative or disrespectful behaviors toward Latino immigrants is warranted, based on the data presented in this research. Rejecting or disrespectful communications create barriers to health care access and subsequently can contribute to negative health outcomes.

A patient centered approach is one that respects the patient's cultural health care beliefs and practices. A significant part of providers' professional responsibility is to advocate for safe, respectful, and adequate health care for all patients. One way providers can deliver appropriate health care to this population is by showing interest in their illness models, and by being more holistic and socially-based than is customary in standard biomedical care. For example, providers can support patients' cultural health beliefs by first acknowledging that differences exist; such acknowledgement alone can impact health, and health care relationships.

Providers can express interest in this population's health by making a concerted effort to integrate Latinos illness beliefs and practices into their health care experience. Rather than ignore the documented differences in cultural care perspectives in this population, which often results in a mismatch of care expectations between the patient and provider, providers have a responsibility to carefully inquire about the patients' illness beliefs and concerns. Providers should evaluate and negotiate potential mismatches between Latinos' illness beliefs and the provider's biomedical model. Efforts to deliver high quality care to this population require education regarding the different ways Latinos experience, cope with, and treat illness. Rather than discounting the important linguistic and cultural practices (i.e., cultural foods, herbal remedies), providers would do well to incorporate patients varied beliefs into a holistic plan of care.

Providers should encourage their NES/LEP Latino patients to communicate cultural perspectives on health, such as a belief in and use of herbs. As well, providers should elicit

information about patients' constraints on their receipt of care. It is unlikely that any provider who cared for the patients in this study appreciated the fear associated with travel to the clinic, resulting from being undocumented, and uninsured. If these fears were appreciated, providers might have attempted to give all-encompassing care in a single visit, to expedite the report of laboratory results to patients at the point of care and to provide meaningful treatments that addressed patients' questions and concerns.

Health care providers can deliver better quality care to this population by acknowledging and respecting their time constraints, such as obligations to employers and extended family members. Considering informants' experiences with excessive wait times to see providers, clinic processes discounted the fact that patients had multiple demands on their time, and were making significant sacrifices in their attempts to get care. Providers can additionally acknowledge Latinos' feelings of being invisible in health care centers by taking a moment to communicate clinic constraints (i.e., high patient volume), that delayed care rather than ignore the fact that patients might have waited for hours. Providers can additionally communicate the importance of follow up care and how patients can overcome barriers to receipt of that care.

When working with NES/LEP Latino patients, providers can remind patients that care doesn't end when they leave the clinic. Providers can clearly communicate both verbally and in writing, for patients and family members, how adequate follow up care can be obtained. Providing timely follow-up appointments would help tremendously. Keeping an updated phone number for each patient would allow the provider an option to call the patients to evaluate why they were unable to take advantage of follow-up care.

Providers can increase Latinos' understanding of their care by requesting the assistance of non-licensed Spanish speaking health clinic staff. For example, if a patient's health does not

improve after several encounters with a provider the NES/LEP Latino patient may require additional education about illness, and health care options. Providers with time constraints can refer Latino patients to a Spanish speaking health educator or non- licensed personal (i.e., Promotora), within the clinic. Finally, providers have a professional duty to promote patients understanding of their care by utilizing appropriate language services.

**Language.** In California, health care providers are required by law to utilize professional interpreters when caring for the NES/LEP population. Professional interpreters permit NES/LEP Latino patients and providers the opportunity to establish rapport, and work at building a trusting relationship. Providers who communicate effectively with Latinos patients increase their own understanding of how to approach and care for this population.

Considering that professional interpreters are key to having a clear understanding of the Latino patients' expectations for care and providing informed care to this population, health clinics will need to maintain language services and providers will need to employ them. Educational programs for health professionals must provide learners with a clear understanding of their responsibility to effectively communicate with NES/ LEP and prevent miscommunication of health care information. Adequate translation systems (in-person or telephone-based interpreters,) are necessary to avoid serious misunderstandings about the patients presenting complaints. Similarly serious misunderstandings on the patient's part about the diagnosis or expected treatment, can only be avoided if there is fluent interpretation.

Providers can inform patients about their care via effective communication. In fact, in an effort to advocate for cultural and linguistic care for all patients, providers might consider refraining from prescribing medications, or consenting this population for surgical interventions, in the presence of language and culture barriers, apart from severe acute illness (i.e.,

appendicitis). Provider time constraints create barriers to patient provider communication that negatively affect the care to this population. However, provider time constraints don't warrant the use of ad hoc or family interpreters.

Advocating for high quality cultural and linguistic care requires that providers be given time to communicate with their NES/LEP patients. For example, providers require time to investigate the types of care this population prefers (i.e., holistic), and types of care they would rather avoid (i.e., strong medication, surgery). Providers can work with time constraints and still provide linguistic and cultural care by reviewing the patients chart and history of illness before entering the exam room. Also, any previous information about Latino cultural practices is helpful.

Providers should address this population by their last names and take moment to introduce themselves as the person caring for them. Last, it may be necessary for providers to utilize a first, and possibly a second patient appointment to get to know the Latino patients, and their illness story, except when severe illness is present.

Listening to Latinos' illness stories is key to providing linguistic and culturally appropriate health care. One way providers can get to know this population is to ask the Latino patients why they believe they became ill. In addition, providers might offer health care options that are in line with common cultural health beliefs (i.e., education about wellness, less medication). Last, to provide effective care providers should show interest and concern for the barriers to health that patients experience, such as being uninsured and poor.

Providers should be aware that Latinos who have negative diagnostic exams or are unable to access a diagnostic exam (i.e., EGD), often continue to suffer from severe illness symptoms and health concerns. Therefore, providers should clearly communicate to patients if a solution

for their illness concerns is lacking due to financial or regulatory constraints. Providers who have multiple encounters with Latino patients that clearly have not benefited from medications or dietary changes might consider referring these patients to the clinic psychologist to evaluate other concerns (i.e., stress related to deportation and poverty).

Providers who refer their NES/LEP Latino patients to another provider have a responsibility to inform the provider in a referral note that the patient will require a professional interpreter. Although treatment and health care payment provisions are constantly shifting, providers should refrain from referring non-documented and uninsured Latino patients to specialists if these departments will not accept uninsured patients with non-emergent illness concerns. Referring this population to doctors who don't take uninsured patients or don't provide language services only serves to break patient-provider trust and discourages patients' efforts to engage follow up care. Instead, providers can show concern for Latino's resource constraints, by offering the patients evidenced -based care via covered services or providing care at a much reduced price (i.e., guaiac stool, blood test, sigmoidoscopy in office). Finally, providing health care across language and cultural barriers to this population has ethical implications for nursing practice.

In every situation providers have an ethical and moral responsibility to advocate for good safe care for all patients regardless of the system limits. Use of professional interpreters with NES/LEP patients is required by law because these interpreters remain a critical part of providing safe care to this population. Hence, providers who are unable to access language services while caring for NES/LEP patients have a moral obligation to document these incidents. For example, providers can evaluate the system level constraints that can be modified to provide linguistic and culturally appropriate care to all patients.



**Systems level modifications.** Creating an all-inclusive safe environment within health care centers in the United States requires that the health care center climate feel welcoming and safe for all patients. For instance, when undocumented Latino immigrant patients arrive to the health care center clinic staff should greet them in a polite way and make eye contact. Furthermore, bilingual front desk staff should inform the NES/LEP patient when they check in that an interpreter will be necessary and therefore provided to them free of charge.

At the point where the NES/LEP Latino patient checks in for a clinic appointment the front desk receptionist should notify the professional interpreter or assure that a phone interpreter is made available for the patient and their provider. In fact, at the system level scheduling NES/LEP patients for clinic appointments should be avoided unless a professional interpreter will be made available to this population.

To create an inclusive environment in the clinic the health care center can schedule NES/LEP Latinos health care appointments with a provider and professional interpreter. One example, is when the clinic schedules a deaf patient they also schedule a professional interpreter so both the patient and their provider can effectively communicate. In fact, deaf patients do not see providers without a professional interpreter as this would be considered unsafe, unlawful, and unethical practice, aside from an emergency situation.

Latino immigrants experience a great deal of fear and discomfort when visiting US health care centers. Another way to create an inclusive environment is to limit the requests for personal information in health centers when possible. For instance because some Latino immigrants' fear being reported by front desk staff, a system modification should limit desk receptionists from collecting unnecessary personal information. As well, front desk receptionists should inform the NES/LEP Latino patients that any personal information they provide will not be shared with

anyone outside the clinic. Limiting the information gathered to only the most necessary information serves to protect this population's privacy and increase their feelings of safety while receiving care. Lastly, clinic staff should respect the fears and constraints that non -documented Latino immigrant patients, and their families experience by refraining from disrespectful behaviors that only increase this populations stress and fear.

Clinic health care staff should be trained to provide patient-centered care. For example, clinic staff can be provided training to understand what respectful care looks like when interacting with Latino immigrant patients. Clinic staff who are disrespectful, should be provided in-services that educate them in ways to communicate respectfully especially with NES/LEP undocumented population.

Continuity care, with a stable set of providers is another way to provide culturally appropriate care to this population. Since many Latino patients believe that the success of their treatment is based in part on the quality of relationship and understanding they have with their provider, systems should avoid giving patients multiple appointments at different health care center locations or with different providers, whenever possible. Obviously optimal care for NES/LEP Latino patients would be with language-matched providers. However, stable relationships with non -Spanish speaking providers' increases the possibility of having providers know their patients well. Finally, continuity of care can be accomplished once health care centers and providers appreciate the importance this population places on their ability to establish rapport and trust in their providers care. Finally, nurses who are educated regarding the devastating effects that language and cultural barriers have on Latinos' health, and health care can better advocate for this population.

**Implication for Education.** Considering the rapid growth projection for Latino immigrants living in the US providing education to nurses regarding the barriers faced by this population is warranted. For example, in the nursing curricula information regarding how to approach and care for LEP/NES immigrant patients amidst system constraints (i.e., lack of language services) is appropriate.

One consideration when preparing future nurses to care for NES/LEP Latinos immigrants is to diversify nursing curricula at both the undergraduate and graduate level. For example, providing a nursing education that is underpinned by evidence based knowledge regarding the many ongoing constraints faced by the Latino immigrant population especially undocumented Latinos is warranted. Finally, educating nursing students regarding pertinent laws in place to protect the NES/LEP patient population is reasonable.

To increase nurse's knowledge about how to provide appropriate care to Latino immigrants nursing student require specific course content regarding immigrant health and health care. For example, specialty options could be made available to nursing students who chose to provide care to immigrant population. Moreover, nursing students could have an additional option to take a language course depending on the population students are expected to care for (i.e., Spanish). Finally, nurses armed with knowledge regarding the laws and regulations in place to protect vulnerable patient populations can better advocate for safe and effective care for all patients in the presence of system constraints.

Nursing education that encompasses knowledge regarding the importance of laws and regulations to protect patients is warranted. In order for nurses to advocate and provide care to this growing population they require concrete instruction on core laws enacted to protect patients. One example is the Emergency Medical Treatment and Active Labor Act (EMTALA).

This Federal policy was mandated due to the practice of “patient dumping” or because hospitals were refusing to care for patients solely based on poverty, lacked insurance and or due to the patients’ non- documented status (Flaskerud and Calvillo, 2007).

Increasing the educational hours for course content in ethics and caring is warranted considering the health disparities suffered by the NES/LEP populations. Finally, further research is needed to understand how to reduce linguistic and cultural health care disparities in this population. However, due to this population fears of being arrested and deported researchers must have a good understanding how to gain access to this population.

**Implication for Future Research.** To gain access to non-documented Latino immigrants researchers must have someone on their research team, the PI or data collector who has a deep understanding of the culture. Especially with very threatened populations its likely researchers will require a liaison to the community.

I am a Latina, speak Spanish and was raised in migrant farm housing in the same area where I conducted my study in the Central Valley CA. A great deal of my research time was spent gaining the trust of the community leaders (i.e., Priest, Nuns), and finally the Latino immigrant populations.

As a Latina researcher I found it very difficult and time consuming to gain access to this population. Consequently, researchers might consider allocating more research time for their project to connect with important community leaders (in my instance the local , Priest). Also, researchers may need to consider that Latino immigrants are often Catholic. Therefore, the researcher should have someone on their research team who is Catholic that could facilitate an authentic entree into the lives of this population via the Catholic Church.

The Catholic Priest and Nuns may consider helping researchers gain access to undocumented Latino immigrants only after the church leaders are certain these researchers will not harm the immigrants, and can show their willingness to be a part of the Latinos immigrants' daily lives. For example, on numerous occasions during my study a great deal of time was spent sharing meals in the houses of participants as a way to continue my relationship with this population.

As a researcher I was given several projects by the Priest and Nuns to show my willingness to be a part of the community. For several months I worked on these projects (i.e., three health fairs), that directly placed me in the center of the Latino immigrant population for recruitment. Only then, in a non-threatening environment after months of contact with the population did potential participants approach me about being in my study.

Researchers will need to take into account the difficulty in recruiting a population of immigrants that are being actively pursued by immigration officials, and deported at record levels. The population trust level for American Latinos appeared very low. Consequently conducting research with this population requires that investigators develop a rapport and trust with the leaders of the Latino community where these immigrants have taken refuge in hopes for protection.

As a Latina researcher I found myself forced to reveal that I too was Catholic to gain entrée to this population. Researchers may find the need to answer very direct questions about any previous relationships they may have had with the immigrant population. For example, I was asked by potential participants to describe my work as a child in the fields even what fruit my family picked and from what town we picked it.

Researchers who are not Catholic and have never made contact with this population to date may have increase difficulties recruiting this population at least in the Central Valley CA. Ways investigators can improve recruitment of this very hard to reach population includes the use of a church liaison for the entire research project. Furthermore, having someone on the research team who has been a farm laborer and knows the area where the immigrants are living is very helpful to build trust, and rapport with this population and community leaders.

Investigators who want to access and study this population should be prepared to answer direct questions about their religious beliefs and practices. Consequently, having a member of the research team that is Catholic is warranted due to this population deep seated beliefs in the protection of Saints, and the Catholic Church. As a Latina researcher I found myself in the uncomfortable position of revealing that I too believed in the Mother (Virgin Mary), in my need to gain access to several participants all of whom had a Virgin Mary statue in their homes.

Researchers might allow more time to conduct research with undocumented Latino immigrants as the populations is often extremely cautious when speaking to anyone not living in their communities. For example, to communicate with Latinos on multiple occasions I was asked to volunteer my time for the Catholic Priest who obviously promoted the health and wellbeing of all Latinos immigrants in his community.

To access Latinos immigrants researchers may need to allow several months to work with their community leaders. As a researcher I took part in three health fairs where I provided health care to approximately 160 undocumented Latinos. The people from Mexico who attended these health fairs said that they had spoken to the Priest, who informed the Latinos about, the nursing student who came to help the people and hear about their illness.

The most prominent Latino community leader for immigrants was the Catholic Priest followed by the nuns, and finally the church liaison. As a Catholic Latina researcher eventually I was able to access and study this population. However, not before I became deeply rooted in the day to day lives of this population and their community leaders.

Non-Latino researchers who want to study this hard to reach population will need to work closely with Latino community leaders for the entire study if these investigators want Latinos to stay interested in participating in their project. For example, I attended mass at the Catholic Church regularly and participated in several events at the Church. One very significant all day event was the 1 year anniversary of the Patron Saint of Immigrants, "*Toribio Romo*". This Saint from Mexico is believed to appear to the Mexicans, and provide protection to the people when they cross the border into America. Finally, participants appreciated that I understood the "icon used by the Mexican American people for the hope of food, water and money, as well as safety" (Gutierrez, Marco A. Garcia, 2002).

### **In Summary**

The implications for practice for health care providers clearly involves advocating for linguistic and cultural appropriate care for all patient. Providers will need to acknowledge systems level constraints (i.e., lack of language services), and ways to modify these systems in order to create an all-inclusive environment in the health care centers. The university might consider the implications for education by graduating nurses who can provide direct care to this rapidly growing Latino immigrant population. For example, increasing undergraduate and graduate level nursing courses specific to immigrant health, and health care are warranted. Furthermore, researchers who are considering studying this hard to reach population can better gain access to this population via Latino community leaders. Finally, researchers would benefit

from having a Latino Spanish speaking Catholic researcher or data collector and a church liaison on their research team.



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## APPENDIX A

## University of California, San Francisco

## Interview Guide

**Title:** Exploring the Expression of Pain by Limited English Proficient Latino Immigrants in Language and Cultural Discordant Health Encounters.

Thank you so much for agreeing to speak with me. I would like to learn about your experiences with your doctor or nurse regarding your abdominal pain. I would like to hear about what these experiences are like for you.

**Interview Questions:**

First, I would like to get a brief history of your abdominal pain and treatment.

1. Can you tell me when you first started to experience abdominal pain? How many incidents of pain have you had over the years? Can you describe in general the diagnoses and treatments you have received for this pain over this time.
2. Now I would like to focus on the last year. Can you estimate how many times in the past year you have experienced abdominal pain, which led you to seek health care? Please describe where you sought care for this pain? What kinds of diagnoses and treatments did you receive in the last 12 months?
3. Please tell me what it is like when you seek health care for your abdominal pain.

Probes: What has been your overall experience in care of your GI pain?

What has been the quality of care you have received?

What aspects of care have been most helpful?

What aspects of care have been least helpful?

Can you describe how your language or culture may have influenced the care you received?

4. Please tell me about a time when you visited a clinic (ED, hospital, outpatient clinic) for abdominal pain and felt you received good care and treatment. Please just tell me the story of what happened. (Obtain full narrative from participant's perspective.)

Probes:

- A. What happened next? What was that like for you? How did you feel about that? What did you do?

- B.** Please discuss the communication between you and the provider in this incident. What worked well in the communication? What didn't work so well or could have been improved?
  - C.** In this clinic visit who or what helped the most? Who or what stood in the way of your getting good care?
  - D.** If you had it to do over, how might you change things in this clinic visit? What might you say or do differently to make things go better? What might the provider say or do differently to make things go better?
5. Please tell me be about a time when you visited your provider for abdominal pain and felt that you did not receive good care or treatment. Please tell me the story of what happened.

Probes:

- A.** A. What happened next? What was that like for you? How did you feel about that? What did you do? (Obtain full narrative from participant's perspective.)
- B.** Please discuss the communication between you and your provider in this incident. What worked well in your communication? What didn't work so well or could have been improved?
- C.** In this clinic visit who or what helped the most? Who or what stood in the way of your getting good care?
- D.** If you had it to do over, how might you change things in this clinic visit? What might you say or do differently to make things go better? What might the provider say or do differently to make things go better?

Now I would like to ask some questions about your illness.

- 6. Can you tell me how you understand you illness? What led up to it and how did it develop
- 7. You know there are many different explanations for what abdominal pain is all about. I'm interested in your understanding of the illness.
- 8. Could you describe the first things he noticed about years yourself that made you suspect that there was something different or that there was a problem? Why do you think it started when it did?
- 9. What do you think might have caused these problems or differences?
- 10. How severe is your sickness? What do you think the course of the illness will be?
- 11. What kind of treatment *should* you receive? What are the most important results you hope to receive from this treatment?

12. What do you fear most about your illness?
13. What are your hopes and desires for your future?

Thank you for your participation

## APPENDIX B

**University of California, San Francisco**

## Demographic Questionnaire

**Study Title:** Exploring the Expression of Pain by Limited English Proficient Latino Immigrants in Language and Cultural Discordant Health Encounters

Date of Record \_\_\_\_\_

Participant ID (#) \_\_\_\_\_

Location of Interview \_\_\_\_\_

- Diagnosis associated with abdominal pain \_\_\_\_\_
- Date of diagnosis \_\_\_\_\_
- Year of onset of symptoms of abdominal pain \_\_\_\_\_
- Number of hospitalizations for abdominal pain \_\_\_\_\_ (year)
- Age \_\_\_\_\_
- Gender \_\_\_\_\_
- Marital Status: \_\_\_\_ Single \_\_\_\_ Married \_\_\_\_ Divorced \_\_\_\_ Widowed
- Religion \_\_\_\_\_
- Occupation \_\_\_\_\_
- Length of time in Fresno \_\_\_\_\_
- Length of time in California \_\_\_\_\_
- Length of time in the U.S. \_\_\_\_\_
- Health Care Coverage \_\_\_\_\_

## APPENDIX C

**University of California, San Francisco****Consent to Participate in a Research Study**

**Study Title:** Exploring the Expression of Pain by Latino Immigrants in Language and Cultural Discordant Health Encounters.

This is a research study about how Latinos report abdominal pain to their providers. Jacqueline Lopez Gregory, FNP-C MS, PhD(c) is a doctoral student in the School of Nursing at UCSF and her research is being supervised by Dr. Catherine “Kit” Chesla, RN, DNSc, FAAN from the Department of Family Health Care Nursing. Please take your time to make a decision about participating, and discuss your decision with your family and friends if you wish. If you have questions regarding the study, you may ask the researcher. You are being asked to participate in this study because you are Latino, speak Spanish and have experienced abdominal pain that you reported to your health care provider.

**Why is this research being done?**

Information is needed to improve care of abdominal pain in Latinos. The purpose of this research is to understand the communication of symptoms and treatment between Spanish speaking Latinos and their providers who do not speak Spanish.

**How many people will take part in this study?**

About 15-20 people will take part in this study.

**What happens when I take part in this study?**

If you agree to participate in the study the following will occur:

- The researcher will interview you for 2 hours in a private area that is convenient for you. You will be asked questions about your experiences when you reported abdominal pain to your provider. You will also be asked questions about your history of abdominal pain. You may be asked to participate in a second interview
- The researcher will tape record the conversation. After the interview, a transcriber will transcribe the collected information and will replace any names with a code number.

**How long will I be in the study?**

Participation in this study will take approximately 2-4 hours over 3 months. The researcher may ask you to participate in a second interview. The second interview will last approximately 2 hours.

### **Can I stop being in the study?**

Yes. You can decide to stop at any time.

Also, the study researcher may stop you from taking part in this study at anytime if he or she believes it is in your best interest.

### **What risks can I expect from being in the study?**

- You may feel some emotional discomfort during the interview. The environment will be relaxed. There is no right or wrong answers, and you will have plenty of time to think about what you might want to say.
- You may ask the researcher to stop the interview at any time if you feel uncomfortable.

### **Are there benefits to taking part in this study?**

There are no direct benefits to you for participating in the study. However, the information you provide may help the researcher understand how Latinos report symptoms of abdominal pain and how they work with providers to treat that pain, valuable information to better serve the Latinos.

### **What other choices do I have if I do not take part in the study?**

You are free to choose not to participate in the study. If you decide not to take part in this study, there is no penalty to you and it will not affect your relationship with or care in the GI clinic.

### **Will information about me be kept private?**

We will do our best to make sure that the personal information gathered for this study is kept private.

Organizations that may look at and or copy your research records for research, quality assurance, and data analysis include:

- UCSF School of Nursing
- UCSF Committee on Human Research

### **What are cost of taking part in the study?**

There is no cost to you as a result of taking part in this study.

### **Will I be paid for taking part in the study?**

Yes, participants will be given a \$10.00 in cash at the end of each interview.

### **What are my rights if I take part in this study?**

Taking part in this study is your choice. If you decide to take part in this study, you may leave the study at any time. No matter what decision you make, there will be no penalty to in any way.

**Who can answer my questions, comments or concerns about taking part in this study?**

If you have any questions, comments, or concerns about taking part in this study, first speak with the researcher Jacqueline Lopez Gregory (805-710-4350), or Dr. Catherine “Kit” Chesla, (415-476-4439). If you still have concerns after doing so, you may contact the office of the **Committee on Human Research**, UCSF institutional review Board. You can reach the CHR office at 415-476-1814, 8am to 5 pm, Monday through Friday. Or you can send a letter to: Committee on Human Research, P.O. Box 0962, University of California, San Francisco (UCSF), San Francisco, CA 94143.

**Consent**

PARTICIPATION IN RESEARCH IS VOLUNTARY. You are free to decline to participate in this study or to withdraw at any time without penalty or loss of benefits to which you are otherwise entitled.

If you agree to participate please sign below. You have been given a copy of this consent form to keep for your personal records.

Date	Signature of Study Participant

Date	Signature of Person Obtaining Consent



## APPENDIX D

**University of California, San Francisco**

Exploring the Expression of Pain by Limited English Proficient Latino Immigrants  
in Language and Cultural Discordant Health Encounters.

**Study Information Sheet**

Dear Patient:

Ms. Jacqueline Lopez Gregory, a Nurse Practitioner and doctoral student at UCSF, is studying the experiences of adult Latinos who go to the GI clinic and report symptoms of abdominal pain to their providers. She would like to speak with you about participating in her study. Ms. Gregory is Latino and speaks Spanish and understands the importance of effective communication between Latino patients and their nurse or doctor.

If you decide to participate in the study:

1. Ms. Gregory will interview you in Spanish for 2 hours in a private location that is convenient for you. You will be asked questions about your experiences of abdominal pain with your nurse or doctor. You may be asked to participate in a second interview. You are free to discontinue participation at any time. You will be paid \$10.00 to thank you for your time.

If you are willing to discuss this study you can

- Contact Jacqueline Gregory at (805-710-4350)

Whether you decide to be a part of the study or not, your care at the GI clinic will not be affected. All results will be kept private (confidential). Thank you for valuable time and help with this study.

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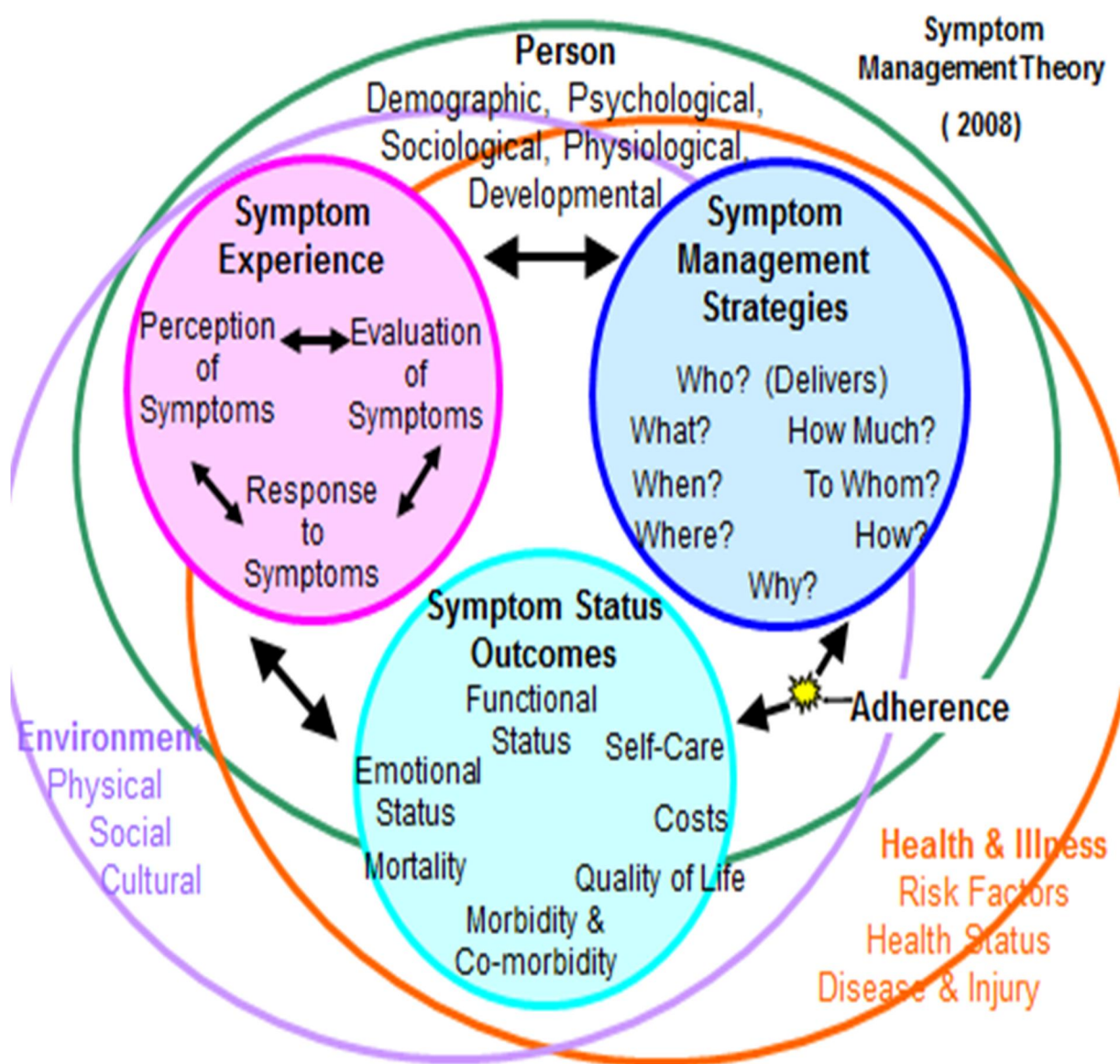
Please print your name

APPENDIX E

**University of California, San Francisco**

Exploring the Expression of Pain by Limited English Proficient Latino Immigrants in Language and Cultural Discordant Health Encounters.

**Symptom Management Model**



## APPENDIX F

## University of California, San Francisco

Exploring the Expression of Pain by Limited English Proficient Latino Immigrants  
in Language and Cultural Discordant Health Encounters.

## Demographic Overview

Pseudonym	Age	Number of years suffered from abdominal pain	Diagnostic and surgical treatments received	Work	Estimated years living in United States of America	Immigrant status
Anna	49	5	ERCP,EGD cholecystectomy	Packing house/factory	19	Non- documented
Ema	55	3	None	Unemployed	9	Non- documented
Tera	52	8	Ultrasound, Birth control	Factory worker	11	Non documented
Rempro	58	6	Cholecystectomy	Farm laborer/janitor	23	Non- documented
Rosa	44	5	Medication only	Hair dresser	20	Non- documented
Carlos	35	6	KUB/X-ray	Farm laborer	10	Non- documented
Mare	49	20	Labs	Home maker	23	Non- documented
Maria	63	20	Labs	Home maker	41	Non- documented
Teri	51	30	EGD, H-pylori test balloon test and medications	Disabled	20	Non- documented
Maro	66	20	EGD, colonoscopy, labs, Medications	Self-employed Gardner	38	Documented since 1980's
Dalia	48	2	Ultrasound, Labs, medications	Disabled at home	18	Non- documented
ETA	37	1.5	Medications only	Home maker	15	Non- documented
Mario	64	6	Medication only	Migrant farmworker boss	38	Non- documented

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*Dr. Jacqueline L. Gregory*  
\_\_\_\_\_  
Author Signature

*January, 05 2016*  
\_\_\_\_\_  
Date