

Care-Seeking Experiences of Undocumented, Mexican Immigrant Women
with Chronic Illness: A Phenomenological Study

by

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Approved:



.....
Committee in Charge

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By

Juliet T. Chandler

To my husband, Marty,
flesh of my flesh, and
bone of my bone...

“If a stranger sojourns with thee in your land ye shall not vex *her*,
you shall not pervert the justice due *her*,
But the stranger that dwelleth with you shall be unto you
as one born among you, and thou shall love *her* as thyself.”
(Deuteronomy 24: 17-18; Exodus 22:21)

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But, above all, *Soli Deo Gloria*.

Abstract

Undocumented Mexican immigrant women in the United States are increasing in numbers, and the causes of the social and health inequalities that afflict this vulnerable group of women remain enigmatic. The Latino epidemiological paradox reflects a deceptively positive overall scenario of wellness, despite the fact that foreign-born Mexican women have a higher prevalence of certain chronic diseases than their U.S.-born counterparts. Current health policies have been created to purposefully exclude undocumented individuals, thus further widening the existing inequities. The research literature focusing on this under-studied group of immigrants is sparse, with the studies being primarily epidemiological in nature, therefore inadequately designed to reveal the origins of the access problem.

The purpose of this study was to understand the phenomenon of the barriers to care experienced by Mexican immigrant women who are forced to exist: (a) without the legal authorization to remain in the United States, (b) having limited or no healthcare coverage, and (c) while suffering from chronic medical conditions. This interpretive phenomenological study examined the healthcare seeking experiences of 26 Mexican immigrant women, employing in-depth interviews and participant observations as sources of data.

The findings derived from the women's narratives centered around several inter-related themes: (a) the failure on the part of healthcare staff and providers to recognize the medical needs of the Mexican immigrant women as legitimate, (b) the situatedness of the women as the defining factor of the healthcare possibilities available to them, and (c) the women's strong *need* to survive, and the value placed on work as the motivation to stay healthy and to provide for themselves and their families. The immigrant women participants experienced multiple

constraints in managing their illnesses, and suffered debilitating effects of their medical conditions. The women responded to the constraints by making accommodations in the way they managed their chronic illnesses, often foregoing needed medications due to expense (or by obtaining them in any way they could), not seeing physicians when it seemed necessary to do so, opting for less expensive self-help techniques, and passing falsified results to gain access to certain medical resources.

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Table 2. Demographic Description of Study Participants

Introduction

I am an immigrant. When I was ten years old, my parents decided to move from the Philippines to the United States. Like most immigrants, this move was prompted by the strong need they felt to broaden their economic horizons (and those of their children). Because my father was granted a professional visa to work here legally, we had a leg up on most immigrant families. My father had earned this right by agreeing to work with a team of Asian engineers for a U.S. company that was based in Saigon during the height of the Vietnam War (the company, understandably, was having great difficulty recruiting Americans at that time). Soon after immigrating to the U.S., my family was met by the economic recession of the early 70's, and my father was forced to work two jobs just to keep the family afloat, while my mother tolerated an assembly-line job that paid minimum wage (at the time less than \$2.00 per hour). While the process of becoming an "American" had been a hard one for me, my experiences growing up in an immigrant home had given me a keen understanding of the plight of many marginalized people, especially those who have not yet fully integrated into the societal mainstream.

I was first introduced to undocumented, Latina immigrants working as a family nurse practitioner at a safety-net clinic in the town in which I reside. There I became intimately acquainted with the daily physical and psychosocial challenges these women face. I gained a deep awareness of the, often, staggering problems facing women who work in the fields, including struggles with illiteracy, poverty, and even sexual abuse and domestic violence.

As a clinician working in a busy migrant health clinic, I remember feeling particularly helpless caring for women who were both undocumented and uninsured, and who also had a chronic illness. I would often send them to the only safety-net program in our area that provides

partial medical coverage for indigent adults, but all the while thinking that they would probably be denied because of their lack of documentation. This fueled my desire to obtain a law degree with hopes that it would better equip me to advocate for these women more successfully-- something I had not been able to accomplish in my clinical practice. However, after earning my juris doctorate degree, I began to realize that perhaps the best way for me to help undocumented immigrants suffering from a chronic illness was to be instrumental in the creation of policies that would improve their health and healthcare access. Thus, one of my primary goals in pursuing a PhD in Nursing was to be better equipped to do policy-related research.

The purpose of this dissertation was to explore the experiences of undocumented Mexican women immigrants with a chronic illness (one of the same populations I have served for 13 years) while they sought medical care in clinics within the local healthcare safety-net system.

Statement of the Problem

Over half of the nearly 45.5 million Latino adults currently living in the U.S. are immigrants (Pew Latino Center (PLC), 2010; Vega, Rodriguez, & Gruskin, 2009). Among the Latino immigrant adult population, approximately 11 million are undocumented; and 38% of the undocumented Latino immigrants are women (PLC; U.S. Department of Commerce, 2007). Undocumented immigrant women (i.e., those who have entered the U.S. [a] without legal authorization, [b] with nonimmigrant visas, or [c] and have violated their legally-obtained visa, and no longer having legal authorization to reside in the U.S.) with chronic illnesses are at a particularly high risk of having poor health outcomes (Derose, Escarce, & Lurie, 2007). Undocumented Latino women encounter more barriers to obtaining preventive and screening services than do non-Latino white women, often resulting in inadequate disease detection, prevention and management (Agency for Healthcare Research and Quality, 2006; Institute of Medicine, 2003; Solis, Marks, & Garcia, 1990). These barriers to healthcare have been linked to increased morbidity and mortality among this subgroup of Latina immigrants (Vega, et al; Freeman & Lethbridge-Cejku, 2006).

Even though chronic diseases such as cancer and heart disease are the leading cause of death among Latina immigrants (Aguirre-Molina & Molina, 2003; Winkleby, Kraemer, Ahn & Varady, 1998), researchers have paid little attention to the barriers faced by Latina immigrants with serious chronic illnesses when seeking care. Also, studies focusing principally on *Mexican* immigrant women are lacking in the research literature. Mexican immigrant women (MIW) have unique qualities that predispose them to higher rates of morbidity and mortality than other Latina immigrants (Vega et al, 2009). MIWs' modes of socioeconomic incorporation and acculturation

into the societal mainstream differ from other Latina immigrants (Kaestner, Pearson, Keene, Geronimus, 2009). In a study comparing immigrant women from five different Latino subgroups, Freeman & Lethridge-Cejku (2006) found that Mexican immigrant women were more likely than all other groups to: (a) be impoverished, (b) have a low level of education, (c) lack health insurance, and (d) have unmet medical needs. Despite the growing number of undocumented Latina immigrants in the U.S., the relationship between their immigration status and their access to, and utilization of, health care services is under-studied (Goldman, Smith & Sood, 2005). Furthermore, there seems to be a growing climate of anti-immigration sentiment in the U.S. This is reflected in the national plan to reform the healthcare system into one which seems designed to exclude undocumented immigrants, thereby increasing the health inequalities that already exist, rather than seeking to abolish them (Martin & Burke, 2010).

Current research has used aggregate level data and epidemiological studies to examine the personal and social processes that create health care access barriers among undocumented, uninsured MIW. However, quantitative inquiries, alone, cannot adequately capture the processes that might play significant roles in increasing social and health inequalities currently being experienced by this vulnerable population. Healthcare professionals and policymakers need an adequate knowledge of the personal and social factors that may contribute significantly to the poor health outcomes and the health disparities that exist in this patient population. More qualitative studies that explore the personal experiences of undocumented immigrant women can help elucidate the barriers to care which confront them. In turn, this critical information can be used by policymakers to create health and social policies that best frame the issues surrounding

access to and quality of care among these women (The 2007/2008 Forum on Migration and Health).

This study addresses gaps in the literature by using a qualitative approach to explore the contextual factors that influence the experiences of undocumented, MIW and the barriers they face in caring for their chronic conditions because of their limited access to healthcare. The research question that guided this dissertation was: How do the lack of documentation and lack of healthcare coverage affect the care-seeking experiences of undocumented, MIW with chronic illness?

Specific Aims of the Phenomenological Study

This qualitative study explored the healthcare seeking practices of undocumented MIW with chronic illnesses using the interpretive lens of hermeneutic phenomenology to help understand their lived experiences. Semi-structured, open-ended interviews of twenty-six immigrant women were conducted in Spanish and the particular indigenous dialect of the participants. The participants consisted of indigenous (i.e., Zapotec, Triqui and Mixteco) and non-indigenous immigrant women who were recruited from a local free clinic and a nearby community of indigenous migrant farm workers. Data analysis of the narratives was done in the phenomenological tradition using thematic analyses, exemplars and paradigm cases. Methodological rigor was maintained with the use of triangulation, prolonged engagement and member-checking.

The specific aims of this interpretive phenomenological study were to:

1. describe the experiences of the undocumented, Mexican immigrant woman seeking healthcare services in the local safety net system.
2. describe the contextual factors (e.g., personal, socio-cultural, linguistic and politico-economic) influencing an immigrant woman's care-seeking practices.
3. describe the experiences of an immigrant woman coping with a chronic illness in her daily life.

This dissertation is comprised of: (a) an introduction with the statement of the problem, specific aims and a description of Heideggerian phenomenology, the theoretical and methodological underpinnings of this study. (b) an article containing a review of the literature describing the health inequalities experienced by undocumented, MIW with chronic illness and

limited access to health care, (c) an article discussing the theme of the lack of recognition experienced by the women while seeking care for their medical needs, (d) an article elaborating on the limited healthcare options consequent to the women's situatedness as well as their intense need to work and provide for their families, (e) a synthesis of the research findings from all three articles, and (f) implications for policy development and future research.

Theoretical Framework

Heideggerian Interpretive Phenomenology: A Way of Seeing

Heideggerian phenomenology is a “way of seeing” things for themselves. It changes the emphasis from ascertaining how we know what we know about the human condition, to answering the question of what it means to be a person, and how people make sense of their world (Leonard, 1994). Heidegger views people as “primarily caught up in living their lives, wrapped up in moods and emotional commitments, in cares and worries, falling into temptation, projecting themselves into possibilities, seeking to make themselves whole” (Moran, 2000, p.228).

Heidegger’s phenomenological aim, in short, is to start from an insider’s perspective, and to allow a matter to reveal itself, or to make itself manifest to the seer. Heidegger referred to human beings as *Dasein* (i.e., the German word for “being-there”), which he intended to mean as everyday human existence. Heidegger was careful to distinguish the meaning of *Dasein* from the usual notion of a mere “conscious subject” (Dreyfus, 1991, Heidegger, 1927/1962). *Dasein* is a ‘Being in the world’ (Dreyfus). Personhood, in the Heideggerian formulation, requires being engaged in relationships with others in a world made up of taken-for-granted transactions involving everyday societal and cultural practices (Dreyfus). Several characteristics separate *Dasein* from the Cartesian disengaged subject, namely that: (a) being is self-interpreting; (b) being is in the world, and (c) being is temporal.

Being as Self-Interpreting

Human beings are *self-interpreting*, according to Heidegger. That is, “a person does not come into the world predefined but becomes defined in the course of living a life” (Benner & Wrubel, 1989, p.41). To be *self-interpreting*, in essence, is not to have a pre-established, pre-programmed path in life. In other words, humans can become what they interpret themselves to be, and take what they consider as essential from their social context (Dreyfus, 1991). We are engaged in “a movement of a life course stretched out between life and death” (Heidegger, 1927/1962, p.427). We inherit an array of situated possibilities which are defined by the social practices of the particular culture into which we were born (Dreyfus).

Several aspects of our humanness are inherently true because we are self-interpreting beings, namely that: (a) we have an embodied intelligence; (b) we share a background familiarity; (c) we have the ability to care or be concerned (Benner & Wrubel, 1989). These concepts will form the basis for understanding the experiences of the participants in this research study as they live as outsiders in a foreign land, without the resources to cope with their chronic illness.

Embodied intelligence. According to the Cartesian model, the body is an entity separate from the mind, and is a mere object of possession. As a consequence, the body is incapable of having intelligence, skilled capacities, or any power to respond to the world (Benner & Wrubel, 1989; Leonard, 1994). In the phenomenological view, on the other hand, the body is continuous with the person; and the self (rather than having a body) becomes embodied, having the capacity to respond to meaningful situations:

This *embodied intelligence* is “rapid, nonconscious, nonreflective”, and has a taken-for-granted quality which only becomes obvious when it breaks down (Benner & Wrubel, 1989, p. 43). An example of when the unconscious, embodied self becomes exposed is during illness. Illness interferes with the individual’s ability to negotiate the world and disrupts its embodiment. The following is an excerpt illustrating this point, taken from an interview with an undocumented woman from this research study. The woman was struggling with blurred vision as a result of retinopathy, and was no longer able to work efficiently at her job:

(Translator speaking): She said she used to work at a hotel but she quit. Her illness began to progress and her vision became blurry and her joints hurt a lot...She can’t wipe the counters as well because of the pain. She leaves spots because she can’t see very well...her vision is cloudy.

Her taken-for-granted *embodied* skill to clean with ease and to discriminate between shiny and smudged surfaces has been impaired by rheumatoid arthritis and uncontrolled, type 2 diabetes.

Background familiarity. Contrary to Cartesian thinking, our understanding of what it is to be human is non-mental. Rather, this understanding is “the result of being socialized into practices that contain an interpretation not exhaustively contained in the mental states of individuals” (Dreyfus, 1991, p.17). We are not consciously socialized by our culture to what it means to be a human being, but rather, through “implicit pedagogy”-through social principles which become embodied in our being, and are, therefore, unconscious (Bourdieu, 1977, p.94).

Care. What makes us human (and allows us to be involved in the world), according to Heidegger, is that things matter to us, or that they have significance and value (Benner &

Wrubel, 1999; Leonard, 1994). Dreyfus (1991) describes *concern* as a “basic characteristic of Dasein that things show up as mattering—as threatening, or attractive, or stubborn, or useful, and so forth” (p. 264). Who we are and what we do are “suffused” with a concern for things (Blattner, 2006). Even our lack of concern for something shows our capacity to care (Dreyfus). Putting it another way, the distinctive cachet which separates human beings from mere artificial intelligence (i.e., robots), is that, machines have neither the capacity to care or *not* to care (Dreyfus, personal communication, February, 3, 2008).

Whereas embodiment and background familiarity answer the question of *how* a person becomes involved in the world, concern, according to Heidegger, accounts for *why* people do what they do, and make specific choices (Dreyfus, 1991). A person is not only involved in the world through concern, but is also defined by it (Benner & Wrubel, 1994). Heidegger (1927/1962) described two kinds of concern: (a) a solicitude that “leaps in” and “takes over for the Other that with which he is to concern himself”, and (b) a solicitude that “leaps ahead” of the Other, “not in order to make away his (or her) care but rather to give it back to him (or her) authentically...” (p. 158-159).

Being-in-the-World

To Heidegger, humans cannot exist without a world. Our fundamental way of being is that we are “always already situated” in the world (Heidegger, 1927/1962). Our abilities to think and feel are made possible by being actively engaged in and constituted by the world (Wrathall, 2005). Insofar as what distinguishes human beings from mere objects or animal life, it is their ability to understand themselves and to do something about their way of being (Wrathall).

The “world,” as Heidegger conceptualizes it, is not what we would normally think of as an objective place. Leonard (1989) described the essence of the Heideggerian concept of world as “the meaningful set of relationships, practices, and language that we have by virtue of being born into a culture” (p.46). These everyday practices are what we depend on for meaning, and use to make things intelligible to us (Leonard).

Thrownness. Heidegger calls the state in which we find ourselves in the world as “thrownness” (or situatedness). The possibilities available in each person’s life is a function of his or her being “thrown” into a particular culture, family, or historical world (Benner, 1994). Therefore, we are not agents free to choose what constitutes our world. Rather, we are constrained by what we can or cannot become by the possibilities the world sets up for us (Benner). Leonard (1994) describes the Heideggerian world as being made up of the linguistic and cultural skills used to articulate meaning and “makes things show up for us” (p. 48).

“World is both constituted by and constitutive of the self...the nonreflective taking up of the meanings, linguistic skills, cultural practices, and family traditions by which we become persons and can have things show up for us at all” (Leonard, p.48).

Heidegger’s concept of “thrownness” is clearly exemplified in the lives of Mexican women I interviewed for this study. It is significant to note that many were born in Mexico, having only humble means. Because of their being “situated” in a life of poverty, they come to U.S., often crossing the border illegally, in search of a better life. Choosing to leave loved ones in Mexico or Latin America, many endure separation and loneliness. Also, because of their lack of resources and opportunity, the participants are unable to read or write in either Spanish or in English. Their lack of education limits their possibilities, committing them to blue-collar jobs

(with only modest incomes, at best) for most of their lives, some as hotel maids, gardeners, or restaurant workers)

Inequalities in Access and Use of Healthcare Services of

Undocumented Latina Immigrants:

A Review of the Literature

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Abstract

The purpose of this article is to review the available research literature examining the existing inequalities in the access and use of healthcare services, and to describe the factors contributing to the barriers to care experienced by undocumented Latina immigrants. This integrative review of the literature revealed that disparities in health care access and utilization of services exist among undocumented Latinos, contributing to the body of evidence that supports the hypothesis that the true Latino health condition might be worse than it appears. More specifically, when compared to their documented counterparts, undocumented, immigrant women: (a) were more likely to be uninsured, (b) were less likely to have a primary care provider or a usual source of care, (c) used less urgent and emergent care, (d) used less preventive services, (e) rated their health poor or fair, (f) reported more unmet medical needs, and (g) expressed a great deal of dissatisfaction with the care they received. The literature discussed in this review contains primarily surveys with large aggregate data sets, with studies over a decade old, that failed to control extraneous factors that can threaten their validity. The literature suggests that other contextual factors might be at play in influencing the barriers to healthcare services among undocumented Latina immigrants. Qualitative studies including the voice of undocumented Latinas are needed to supplement quantitative inquiries in the matter. Thus, undocumented Latina immigrants are an under-studied population and a critical gap in the literature still exists.

Introduction

About 32 million uninsured individuals in the United States (U.S.) are expected to gain access to health care by 2019 (Kaiser Family Foundation [KFF], 2009). The recently enacted Patient Protection and Affordable Care Act was designed to improve the accessibility and quality of health care for many individuals, but not for all (H.R. 3590, Subtitle G, §5601). Undocumented immigrants, for example, are excluded from the benefits proposed in the health reform legislation. Health disparities that prevail among this subpopulation of immigrants in the access to, and utilization of, health care will continue to exist unless policy-makers amend the current law (Vega, Rodriguez & Gruskin, 2009). Health disparities, as defined by the World Health Organization, are the “differences in health which are not only unnecessary and avoidable but, in addition, are considered unfair and unjust” (Whitehead, 1992, p.7).

Undocumented Latina immigrants (i.e., women who have entered the U.S. without legal authorization, entered with nonimmigrant visas, or violated their visas, and do not have legal authorization to reside in the U.S.), experience more barriers to preventive and screening services than do non-Latino, white women, often resulting in inadequate disease detection, prevention and management (Agency for Healthcare Research and Quality, 2006; Institute of Medicine, 2003; Solis, Marks, & Garcia, 1990). These barriers to healthcare have been linked to increased morbidity and mortality among this subgroup of Latina immigrants (Vega, et al; Freeman & Lethbridge-Cejku, 2006).

The purpose of this article is to review the available literature examining the inequalities in healthcare access and use of healthcare services, and the factors

contributing to the access barriers experienced by undocumented Latina immigrants, with the intent to inform healthcare professionals and policymakers.

The article is divided into four sections: (a) a description of the Latina immigrant population, and the unique qualities that predispose them to health disparities (including a brief discussion of the “Latino Paradox”), (b) factors that affect the health status and care-seeking practices of Latina immigrants, (c) a review of selected studies focusing on healthcare inequalities experienced by undocumented Latinos and (d) implications for research and policy development.

Background and Significance

As the largest and fastest growing ethnic group in the U.S., Latinos present many opportunities, as well as challenges, to health care providers and policy-makers. Because of their high birth and immigration rates, the number of Latinos is projected to double in size by 2050, and will comprise 30% of the U.S. population (an increase from 14% in 2005) (Pew Latino Center, 2007 [PLC]; Vega, et al., 2009). In the past decade, Latinos have accounted for over half (50.5%) of the overall population growth in the U.S. Of the nearly 45.5 million Latino adults currently living in the nation, over half are immigrants (Pew Latino Center; Vega et al.). Over 11 million Latino immigrants in the U.S. are undocumented, 38% of whom are women (PLC, 2009; U.S. Department of Commerce, 2007).

Despite the growing number of undocumented Latina immigrants in the U.S., the relationship between their immigration status and their access to and utilization of health

care services is under-studied (Goldman, Smith & Sood, 2005). Ignoring the challenges experienced by undocumented Latinas in accessing care can have detrimental effects-- both short- and long-term--on the rest of the U.S. population. For instance, poor quality of care to the uninsured may have “negative spillover effects...not only through a higher financial burden of uncompensated and charity care,” but also through the reduction in the overall quality of care given to the insured members of that community (Derose, Bahney, Lurie, & Escarce, 2009, p.18). Therefore, crafting health policies that will be effective for all people is vital. This is especially salient because the U.S. population finds itself amidst, what appears to be, a growing climate of anti-immigration sentiment. This is reflected in the national plan to reform a healthcare system which seems designed to increase already existing health inequalities experienced by immigrants, rather than seeking to abolish them.

The authors of the Patient Protection and Affordable Care Act have intentionally disregarded the needs of undocumented immigrants. Key provisions of the law are scheduled to be gradually phased in over the course of the next several years but will ultimately: (a) require that most U.S. citizens and legal residents have health insurance; (b) allow a number of tax credits to those citizens who are below or (relatively) close to the Federal Poverty Level; (c) make coverage more affordable through subsidies gained via one’s employment and/or participation in a cost-sharing, health care “Exchange” (i.e., a marketplace designed to drive down the cost of health care); (d) preclude health insurance companies from denying coverage to people for pre-existing conditions (unless the company is willing to pay a large fine), or putting lifetime limits on an individual’s

coverage; and (e) exempt certain groups of individuals from the mandate to obtain health care insurance (KFF, 2009).

Undocumented immigrants are excluded from most of the benefits proposed by the new law. For example, despite the expansion of many public programs proposed under the health reform legislation, these immigrants will continue to be ineligible for Medicaid benefits. They will also be prohibited from purchasing affordable health insurance through the state-based health care exchanges (KFF).

The Latino Epidemiological Paradox

Although the health statuses of most ethnic minority groups have traditionally been depicted as being worse than for nonminority groups, it has been argued that Latinos do not fit this pattern (Hayes-Bautista, 2003). Several studies have suggested that health outcomes for Latino immigrants in the U.S. are similar to, or better than, those of either U.S.-born, non-Latino whites or their racial/ethnic counterparts (i.e., U.S.-born Latinos), despite the lower socioeconomic profiles, lower levels of education, and poorer access to health care of Latino immigrants (Hayes-Bautista). This phenomenon, referred to in the literature as the *Latino (or Hispanic) Paradox*, has created a conundrum in the healthcare arena (Lopez & Jimenez, 2003; Markides & Coreil, 1986; Morales Lara, Kingston, Valdez, & Escarce, 2002). The paradox, according to Acevedo-Garcia & Bates (2008), is “a pattern of morbidity and/or mortality for a particular group that is at odds with what would be expected given its socioeconomic profile” (p. 103). It is a phenomenon denoting a *residual protective effect* among foreign-born Latinos that is not

explained by the sociodemographic, sociocultural or inherent biological risk factors present in this population (Acevedo-Garcia & Bates).

Despite the positive outcomes for some health indicators, researchers are concerned that this epidemiological paradox may not give an accurate picture of the health status of foreign-born Latinos (Acevedo-Garcia & Bates). This “overall scenario of wellness” (p.38) can be deceiving, potentially masking areas of health where Latina immigrants are most disadvantaged. Vega et al. (2009) found that the morbidity and mortality patterns of Latinos moved toward mirroring that of U.S. norms in subsequent generations. They also identified excess mortality in Latinos for specific disease categories, including diabetes, liver disease (including liver cirrhosis), human immunodeficiency virus, and some digestive and reproductive system cancers (i.e., cancers of the cervix, stomach and liver).

Factors Contributing to Health Care Inequalities among Undocumented Latinas

Personal and Social Factors

This section will focus on contextual factors that have negatively influenced the practices of immigrant populations in accessing and using healthcare services (Derose et al., 2009). Some of those discussed here are the Latina immigrants’: (a) socioeconomic status, (b) sociocultural beliefs and attitudes, (c) level of acculturation, (d) limited English proficiency, (e) lack of health insurance, and (f) fear of deportation/marginalization. These factors have been shown to shape the vulnerability of undocumented Latina immigrants (Derose et al.).

Socioeconomic status. In general, Latino women are twice as likely to live in poverty as non-Latino women (20% versus 11%) (Pew Latino Center, 2007). Latinas who are recent immigrants are even more impoverished than those who are U.S.-born (22% versus 18%). Individuals are classified as being poor when their household income is under the Federal Poverty Level (FPL) (U.S. Department of Health and Human Services [USDHHS], 2004). In California, over one-fourth of Latino immigrant families (i.e., a couple with two children) live with annual incomes below the FPL (even when both parents work) (Wallace, 2007). For example, the average yearly wage for Latino immigrant males is \$19,200 (usually from jobs that are heavily reliant on immigrant labor), while the average for women is only \$13,900 (Latina immigrants make 40% less than their U.S.-born counterparts [USDC, 2006]).

Poor women are more likely to be uninsured and dependent on Medicaid as a source of healthcare coverage (Rodriguez & Carrasquillo, 2003). Women who earn less than 150% of the FPL tend to rely exclusively on Medicaid. Low incomes usually mean that a Latino family has to resort to living in low-income housing and unsafe neighborhoods, both of which can jeopardize health (Marshall, Urrutia-Rojas, Mas & Coggin, 2005). Ethnic groups with the worst health statuses have been shown to be those who have the highest poverty rates (USDHHS, 2004).

Socio-cultural. Among Latinos, cultural factors and ethnic beliefs may play a significant role in creating suboptimal health outcomes. In particular, explanatory models of illness, such as *susto*, as well as cultural values in the form of *pena*, are believed to have a powerful influence over Latino health beliefs and practices (Hatcher &

Whittemore, 2007). Among Latin Americans, *susto* is one of the well-recognized folk illnesses--i.e., cultural expressions for distress made up of a myriad of symptoms and explanatory models relating to different illnesses (Weller, Baer, Garcia de Alba Garcia, & Salcedo Rocha, 2008). *Pena*, a term used to describe feelings of embarrassment over exposing one's body, especially of a female to a male, is thought to be one of the foremost cultural barriers to seeking healthcare experienced by Latina immigrants (Hatcher & Whittemore).

A study by Hatcher & Whittemore (2007) suggested that Latinos often reported an amalgamation of three different domains to help explain the etiology of diabetes that, by nature, were: (a) biomedical, (b) cultural, and (c) religious. For example, among Mexican-Americans, the fundamental cause of type 2 diabetes might be attributed to *susto* (Hatcher & Whittemore). Weller et al. described *susto* as “cultural constructions and codifications for extremely stressful experiences with culturally sanctioned responses to those experiences” (p. 410).

Susto, which literally means “fright illness,” is characterized by a strong emotional response to a traumatic or startling event. This experience is often described by Latinos as a type of “soul loss” (Glazer, Baer, Weller, Garcia de Alba Garcia, & Liebowitz, 2004) or “a loss of a vital substance or force” (Rubel, O’Neill, Callado-Ardon, 1984, p. 48). Based on this worldview, fright is not the only emotion that can become extreme enough to trigger an illness. Other strong emotions such as intense anger (*coraje*), sadness (*tristeza*), or joy (*gusto*) may also elicit an illness, which might occur anywhere from several days to even years after an event (Coronado, Thompson, Tejeda,

& Godina, 2004). Symptoms of *susto* may vary and include “shaking or trembling, agitation, crying, bad dreams, difficulty sleeping, paleness, fear of unfamiliar places and people, (or) general malaise” (Weller et al., 2008, p. 408).

Temperament is believed to be a major factor in one’s susceptibility to *susto*. For example, being young and/or possessing unusual physical strength are thought to protect individuals from succumbing to *susto* (Hatcher & Whittemore, 2007). Rubel et al. (1984) found that patients with *susto* had more diagnoses (280) than non-*susto* sufferers (235) ($p < .01$). The authors noted that individuals with a *susto* had higher mortality rates seven years after diagnosis (though they failed to specify the cause of death for these patients) than did those of the same age and gender who did not have one.

A study by Buki, Borrayo, Feigal, & Carrillo (2004) emphasized the need for health care workers to recognize that *pena* has the potential to negatively influence health outcomes for Latina immigrants. The Latina women in Buki et al.’s study reported that they would not want to take part in breast and cervical cancer screening exams because they were embarrassed about having their bodies scrutinized by a male health care provider.

The underutilization of medical services seen among low-income and immigrant Latinas, especially among indigenous subgroups (e.g. from Oaxaca, a southern province in Mexico), has also been attributed to cultural beliefs that emphasize reliance upon folk practitioners, e.g., *curanderos* (healers), *sobadores* (masseuses), and *yerberos* (herbalists), as well as upon the use of folk remedies (e.g., herbs, teas, and potions) (Iniguez & Palinkas, 2003). Many indigenous Latinas try homeopathic medicines, herbs

and teas. If the members of one's family prove unable to help, then the sick individual might seek out the aid of a curandero before looking for more typical Western medical treatments. Unlike medical doctors, curanderos often turn away patients whom they think they cannot cure with their folk healing practices. Western medicine is often thought of as a "last resort" when someone is trying to find a cure for his or her condition (Andersen, Lewis, Giachello, Aday, & Chiu, 1981; Garces, Scarinci, & Harrison, 2006).

Acculturation. Acculturation is the process of becoming assimilated into the host society, achieved by "the acquisition of the cultural elements of the dominant society-- language, food choice, dress, music, sports, etc." (Lara, Gamboa, Kahramanina, Morales, Hayes-Bautista, 2003, p. 369). Lara et al. attest to the complexity of both defining the acculturation experience and measuring the degrees of assimilation achieved by an individual at a certain point in time. In their review of the public health literature addressing acculturation among Latinos, the authors enumerated several negative health outcomes as a result of the acculturation process. More acculturated individuals had: (a) higher rates of substance abuse, (b) poorer nutrition, and (c) poorer birth outcomes. This negative effect seems to be strongest among Latino women (Vega, Alderete, Kolody & Aguilar-Gaxiola 1998; Velez & Ungermaack, 1989).

Acculturation also had an effect on access to and utilization of health care services (Lara et al., 2005). There were higher rates of health care coverage and access to care among more acculturated Latinos. In fact, those who were more acculturated had twice the utilization rate as those who were less so. The literature point to the fact that Latinos who were both foreign-born and who had also lived in the U.S. less than 15 years

were up to five times more likely not to have insurance coverage than were non-Latino whites (Freeman & Lethbridge-Cejku, 2006; Thamer, Richard, Casebeer, & Ray, 1997). Finally, more utilization of preventive services was associated with more acculturation. Compared with U.S.-born Latinas, those who were foreign-born were less likely to receive either a pap smear or a mammogram in a given year, or report having done a breast self-exam (Lara et al).

Sociolinguistic. Seventy percent of Latina immigrants either cannot speak English or have very limited ability to speak English (Pew Latino Center, 2007). A patient's inability to speak and/or comprehend the language of his/her healthcare providers has been shown to have detrimental effects on that person's health, as well as on the health care needs of their young children (Timmins, 2002; Woloshin, Bickell, Schwartz, Gany, & Welch, 1995). For example, misunderstandings about a treatment plan can result in poor patient satisfaction, poor adherence to medication regimens, and under-utilization of healthcare services (Carrasquillo, Orav, Brennan, & Burstin, 1999; Stuart, Minas, Klimidis, O'Connell, 1999; Woloshin, et al.). Also, certain legal and ethical issues can arise from just relying upon family members and untrained staff to interpret for monolingual patients, such as breaches of patient privacy and propagation of inaccurate information (Timmins).

Timmins' (2002) review of the literature found that language barriers affected three major aspects of healthcare among Latinos: (a) access to care, (b) quality of care received, and (c) health status and outcome. His work supported the notion that language barriers had a negative effect on the quality of care received by Latinos, specifically,

affecting health outcome and health status. Language barriers were linked to overall patient dissatisfaction with the kind of care they received, lessened patient recall of physician's instructions and question-asking behavior, and a decrease in comprehension of instructions on medication use and side effects from their physicians (Derose, 2000; Seijo, Gomez & Friedenberg, 1995). A study by Perez-Stable, Napoles-Springer, & Miramontes (1997) corroborates the results found by the other researchers, namely that patients experience poorer functioning when language discordance exists between them and their health care providers.

Health Care System Factors

Notwithstanding personal and sociodemographic barriers, Latina immigrants must also face a healthcare system that is extremely restrictive towards them (Derose, 2000), and healthcare policies that have been crafted specifically to exclude undocumented individuals from receiving healthcare services (Chavez, Flores, Lopez-Garza, 1992; KFF, 2009).

Health insurance coverage. Among all the racial or ethnic groups in the U.S., Latino immigrants are the most likely to have no health insurance (Aguirre-Molina & Molina, 2003), with 60% being uninsured (U.S. Department of Commerce [USDC], 2006). Over 32% of the nation's 50 million uninsured people are Latino (KFF, 2009). Even though Latinas only comprise 11% of the U.S. population of females, they constitute 29% of the total number of uninsured women. Undocumented Latinas, in particular, have even higher rates of being uninsured than their documented counterparts

(Derose, 2000). The number of uninsured Latinas increased by 81% over the past decade (Rodriguez & Carrasquillo, 2003).

Health insurance status is the single most important predictor of access to care among undocumented Latino immigrants (Iniguez and Palinkas, 2003; Mueller, Patil & Boilesen, 1998). For example, Latinas without health insurance benefits were less than half as likely to receive healthcare services as their insured counterparts (Iniguez & Palinkas). Furthermore, undocumented immigrants are 20% less likely to have a regular source of care than are U.S.-born individuals (Bitler & Shi, 2006). In most cases, undocumented Latinas lack health insurance because they are not eligible for public health programs or safety-net insurance, such as Medicaid or Medicare (Heyman, Nunez, & Talavera, 2009).

The law restricting undocumented immigrants from receiving aid came in the form of the Personal Responsibility and Work Opportunity Reconciliation Act of 1996 (PRWORA) which banned all non-citizens arriving in the U.S. after 1996 from participating in state and local benefits programs (Borjas, 2003). More specifically, PRWORA proclaimed that undocumented immigrants were not eligible for “any retirement, welfare, health, disability...or any other similar benefit for which payments or assistance are provided to an individual, household, or family eligibility unit by an agency of a State or local government” (Public Law No. 104-193, H.R. 3734, 104th Cong., 1996). The only exceptions to the mandate include: (a) health care items and services necessary to treat emergency conditions, and (b) assistance for immunizations and treatment of communicable diseases.

More recently, another edict from the Center for Medicare and Medicaid Services (CMS) went into effect in the summer of 2006 (part of the Deficit Reduction Act [DRA]), requiring documentation proving U.S. citizenship for anyone applying for Medicaid. To gain coverage, applicants had to produce a U.S. passport, a certificate of naturalization or a U.S. birth certificate (Lubell, 2006). The DRA was expected to generate approximately \$140 billion in federal entitlement reductions over a thirteen-year period (2006-2015). However, the intent of CMS, to screen out ineligible recipients from receiving health insurance coverage, has created obstacles, not just for undocumented individuals, but also for others (i.e., children who are citizens) (Ellis & Duchon, 2009). Despite this intent, government-sponsored, safety net programs are the primary sources of insurance for low-income Latinas.

Certain subgroups of Latinas (e.g., undocumented women without children) do not qualify for Medicaid or Medicare (Rodriguez & Carrasquillo, 2003). The lack of healthcare coverage seen among Latina immigrants can be attributed not only to their ineligibility for federal programs, but also to the low rates of employer-based coverage typical of their employment (Rodriguez & Carrasquillo). Although over 40% of Latinas who are recent immigrants to the U.S. are employed, they are often uninsured or underinsured because they work in low-skilled jobs that lack healthcare benefits. Employers who offer little or no benefits are usually smaller companies, offering only part-time employment, or jobs that are “off-the-books” (such as child-care, meat-processing jobs, hand-packers and packagers of produce, and dishwashers). For example,

70% of those who make up part of the farmwork labor force do not have health insurance (USDC, 2007).

Lack of health insurance has been associated with decreased access to routine sources of health care, as well as having unmet medical needs (Rodriguez & Carrasquillo, 2003). This has important implications for women's health, because women tend to make more use of health services than do men, i.e., greater needs for routine screening, unique needs for reproductive services. Women are also more likely to be hospitalized, require mental health services, and rely on prescription medications than men (Lambrew, 2001).

In light of these differences in healthcare utilization, lack of health insurance coverage is more detrimental to the health of some Latinas. More specifically, uninsured Latinas are less likely to receive preventative screening (e.g., pap smears or mammography) than are those who have insurance (Baezconde-Garbanati, Portillo, Garbanati, 2003). Thus, they tend to present with later stages of diseases than do non-Latinas, as well as having higher mortality rates from cancer (Aguirre-Molina & Molina, 2003; Borrayo & Jenkins, 2003; Buki, Jamison, Anderson, & Cuadra; 2007).

Discrimination/fear of deportation. In the wake of the passage of the national healthcare reform law, the state legislature of Arizona enacted Senate Bill 1070 (2010). The provisions of this law are intended “to work together to discourage and deter the unlawful entry and presence of aliens and economic activity by persons unlawfully present in the United States” (Arizona SB 1070, Section 1). Critics of SB 1070 claim that the law encourages racial profiling by providing police officers the authority to: (a)

investigate, detain and arrest individuals they reasonably suspect of being undocumented, even if the decision for such action is based solely on the race or ethnicity of the person (SB 1070, Sec 2B), (b) conduct warrantless arrests of individuals based on probable cause that the individual committed a public offense that makes them deportable (SB 1070, Sec 2E), (c) charge individuals attempting to hire and/or pick up day laborers with a misdemeanor, if such attempts obstruct the flow of traffic (SB 1070, Sec 5), and (d) arrest undocumented individuals applying for work, soliciting work in a public place or performing work in the state (SB 1070, Sec 5C).

Opponents of the Arizona law contend that certain sections of the law are unconstitutional, and thus should be enjoined by the court. They argue that requiring law enforcement officials to detain every person arrested until authorities determine their immigration status unlawfully restricts a detainee's liberty. From a health care standpoint, SB 1070 will deter further undocumented immigrants from accessing medical care. Besides avoiding all legal authority figures, undocumented immigrants also avoid people appearing to have authority, which may cause a person to forego necessary medical services and to isolate themselves from medical professionals for fear of apprehension and possible deportation (Berk & Schur, 2001).

Some have also suggested that living under the perpetual stress of these threats, real or otherwise, has deleterious effects on the mental health of these immigrants (Cavazos-Rehg, Zayas, & Spitznagel, 2007; Sullivan & Rehm, 2005). In a study of acculturation stressors, Finch & Vega, (2003) noted that so-called *legal status stress* played a significant role in an undocumented individual's perception of her health status.

The investigators defined the amount of acculturation stressor an immigrant experienced as being a combination of (a) her fear of being deported, (b) her avoidance of authority figures, and (c) the alienation she felt from family and friends. Those who expressed fear about seeking care due to their immigration status were also less likely to report being able to obtain care than were those who did not have this concern (Berk, Schur, Chavez & Frankel, 2000).

Healthcare Inequalities Experienced by Undocumented Latinos

Capturing the essence of the Latino identity is a challenge for anyone attempting to do research with this population. Rodriguez (2008) noted that Latinos are not monolithic and no one can unequivocally state how far “social networks and social capital formations extend among different national identity groups or among subgroups of the same national identity” (p.6). Studying new, undocumented, or indigenous immigrants can present unique challenges to the researcher. For some of these subgroups, being Latino is a characteristic, attributed to outsiders, and not to themselves (Rodriguez).

Within the research literature, the terms, “Latino” and “Hispanic” were often used interchangeably, although there are immense variations within and between different Latino subgroups. Researchers often used the word “Latino/Hispanic” inclusive of individuals who have widely divergent immigration status, i.e., from U.S.-born to recent immigrants. When doing research, disregarding the different heterogeneity among Latinos, can become problematic, as it leads to an inaccurate view of the health status and healthcare needs of the different subgroups. The U.S. government uses “Hispanic” as an

ethnic label to report census facts about population and health of individuals from Spain, Mexico, Central-America, Puerto Rico, Cuban and for those of South American descent (Hatcher & Whittemore, 2007). Because women from Mexico, South America and Central America who live in the U.S. tend to self-identify as “Latina” (Mayo, Erwin, & Spitler, 2003), this term will be used specifically for the purposes of this article.

Literature Search Process

Four major medical literature databases, PubMed, PsychINFO, Web of Science and Cumulative Index to Nursing Allied Literature, CHICANO, were searched from 1985 to present, using the following medical subject headings (MeSH): “Hispanics”, “Latino”, “Latina”, “immigrant adult”, “healthcare access”, “health care utilization”, “undocumented”, ethnic/racial disparities.

Criteria used for including an article in this review were: (a) the study must have been systematic, using either a quantitative or qualitative approach (published in a peer-reviewed, health science journal), (b) the focus of the study must have addressed racial or ethnic disparities in health, (c) the study must have examined at least one of the following aspects of immigrant health among the Latino adult population, i.e., healthcare access, health insurance coverage, or utilization of healthcare services and (d) the study must have included undocumented Latina women.

Studies were excluded if they: (a) were not performed in the U.S., (b) were conducted among children and pregnant adults (these groups may be eligible for a form of Medicaid), (c) were published before 1994 (certain laws were enacted after 1994 that

curtailed healthcare access for undocumented immigrants), (d) examined a specific chronic disease outcome (e.g. ethnic and racial disparities in type 2 diabetes), (e) examined other issues outside of healthcare access and use of services (e.g., issues surrounding migration), (f) did not explicitly include undocumented Latino immigrants as study participants.

The literature query revealed 19 studies that satisfied the inclusion criteria for this integrative review. Fifteen studies were quantitative in nature, and the remaining four were qualitative. Because of the paucity of research that specifically studied undocumented Latinas, the literature discussed in this article is not limited to this population alone, but also includes studies conducted in the general population of undocumented immigrants. This limitation underscores the need for more research targeting this subpopulation of Latinas.

Quantitative Studies

Marshall, Urrutia-Rojas, Mas & Coggin (2005) used secondary data from a cross-sectional study to compare the socio-demographic and health-related characteristics of documented with undocumented Latino immigrant women. Marshall et al.'s study had been part of a larger study (conducted in north Texas) that included undocumented and documented immigrants of both genders, exploring the disparities in healthcare access and health status among a population of Latino immigrants. (Urrutia-Rojas, Marshall, Trevino, Lurie & Minguia-Bayona, 2006). Marshall et al.'s findings confirmed their hypothesis, namely that undocumented women tended to have lower incomes and educational levels, and had less access to healthcare than did documented women. Other

key findings from the study regarding the status of immigrant women were that: (a) 80.3% of all immigrants did not speak English (less than 5% of the undocumented women spoke English), (b) those who were undocumented were more likely to perceive their health as being poor, and (c) there was very low use of public assistance among the undocumented [particularly services from emergency departments (ED)].

Fuentes-Afflick and Hessol (2009) interviewed 710 documented and undocumented Latinas who reside in the San Francisco area. Their findings supported Marshall et al.'s study, specifically in showing that compared to documented Latina women, undocumented Latinas were more likely to (a) be young in age, (b) have a low level of education, (c) have low incomes, (d) be uninsured, and (e) not have a primary care provider. However, the results regarding a woman's age, education and income may each have been biased by the selection of participants from a convenience sample of Latino women who had recently delivered an infant.

Fuentes-Afflick & Hessol (2009) found no significant difference between documented and undocumented Latinas with regard to self-reported use of urgent and emergency care. However, it should be noted that the lack of health insurance likely affected a woman's use of urgent care services, uninsured women being less likely to use urgent care services than those having private insurance. The authors also found that Latinas who were undocumented and uninsured were less likely than were Latinas who were citizens to get preventive health care (e.g., a physical examination or check-up) and dental care (e.g., going to a dentist's office or clinic). Fuentes-Afflick & Hessol's results were consistent with findings from earlier studies that also indicated that undocumented

Latinas use less preventive services than documented Latinas because they lacked health insurance and did not have a usual source of care (Chavez, Hubbell, Mishra, Valdez, 1997; Iniguez & Palinkas, 2003; Rodrigues, Vargas Bustamante & Ang, 2009).

Vargas Bustamante et al. (2010) studied the effect that legal status had on healthcare access and utilization for Mexican-born immigrants. Their findings revealed that 88% of the disparities between undocumented and documented Mexican immigrants were linked to socioeconomic and demographic differences between the two groups. For example, an undocumented immigrant, as compared to one who possessed documentation, was more likely to be young, unmarried, indigent, uninsured, less educated, less proficient in English and to have spent less time in the U.S. The authors also noted statistically significant differences in healthcare access and utilization. Documented immigrants reported having more doctor visits in the past year prior to the study than undocumented immigrants (76% vs. 56%; $p < .01$) and had a usual source of care than their undocumented counterparts (68% vs 46% ; $p < .01$). These findings concurred with the results of two earlier studies by Freeman, and Lethbridge-Cejku, (2006) and Goldman, Smith & Sood (2006). Freeman et al.'s study specifically focused on Latina immigrants, comparing access to health care services across different subgroups of Latino women of varying documentation statuses with non-Hispanic white and non-Hispanic black women. Freeman & Lethbridge-Cejku also found that, among the Latino women they studied, those who were undocumented and uninsured had the highest rates of unmet medical needs.

Ortega et al. (2007) used data from the 2003 California Health Interview Survey, comprised of telephone interviews with 42,044 adults (1588 who self-reported as undocumented). The investigators compared access to health care, use of services, and health care experiences for Mexicans and other Latinos with different types of citizenship or immigrant authorization (i.e., [a] U.S.-born citizens, [b] naturalized citizens, [c] people with green cards or [d] people who lacked any documentation). The results of Ortega et al.'s study showed that undocumented Mexicans were less likely to have a regular source of care (66%, $p < .01$) or health insurance (47%; $p < .01$), nor to have visited an emergency room (14%; $p < .01$) than were those with some type of documentation. In the previous year, these undocumented immigrants were more likely to: (a) have had a lower mean number of physician visits (64%, $p < .01$), (b) have reported difficulty in understanding their physicians (12.3%, $p < .01$), (c) have had problems obtaining necessary health care (18%, $p = .03$), and (d) have perceived that they had received inferior care because they were Latino (20.3%, $p < .01$). However, a unique finding of the study was that foreign-born immigrants, in general, when compared with U.S.-born Latinos, reported fewer problems accessing care when needed, and rated the quality of the care they received higher (which the authors considered to be counter-intuitive). The researchers attributed their results to the possibility that the immigrants they studied had made fewer attempts to obtain care; and when they did, they tended to be more satisfied with the care they received in the U.S. than with the quality of care available in their home country.

Berk, et al (2000) studied the potential burden of publicly-funded healthcare services by undocumented Latino immigrants on the U.S. healthcare system. Their study revealed that, in general, when compared to the rates among other Latinos living in the U.S., undocumented Latino immigrants received fewer ambulatory care visits, as well as had lower rates of hospital admissions (except those related to childbirth). Overall, the undocumented immigrants in their study had less physician visits per year than did other Latinos. Furthermore, fewer undocumented Latinos were enrolled in safety-net health programs, such as Medicaid. Berk et al.'s study dispelled the commonly-held misconception that government-funded health care services provide incentives for undocumented Latino immigrants to come to the U.S. It is unlikely that excluding these services would lessen immigration, since many come seeking employment and a better life.

Studies by Hubbell, Waitzkin, Mvishra, Dombrink, & Chavez (1991) and Ku & Matani (2001) both provide data about undocumented Latino immigrants that is consistent with the findings of Berk et al. (2000). All three studies found that being undocumented had a significant correlation to having reduced access to ambulatory health care (about half the rate of Latinos who are U.S. citizens). Undocumented individuals were also less likely to have a primary care provider or to be registered in a health maintenance organization. These studies cast doubt on the prevailing assumption that individuals with less access to primary care services frequently use emergency departments for routine care. In fact, Nandi, Galea, Lopez, Nandi, Strongarone & Ompad (2008) found that, to the contrary, the use of emergency services was associated with

greater health care need among undocumented, Latino immigrants, rather than for routine care (one possible explanation for this is that many delay seeking care until their illness is severe enough to necessitate emergency care).

Qualitative Studies

Of the four qualitative studies in the literature examined the healthcare experiences of Latino immigrants, only two focused specifically on Latina immigrant women (Derose, 2000; Menjivar, 2002). Menjivar examined how 26 indigent Guatemalan immigrant women (the majority of whom were undocumented) managed their medical conditions without having health insurance or access to resources in the formal health care system. Like the women in Derose's study, Menjivar found that the *Ladina* women developed intricate local and transnational social networks. The women relied on social relations to procure a combination of biomedical and traditional home remedies from Guatemala to treat their medical conditions. Similarly, in an earlier study by Derose, the immigrant women participants (whose documentation status was not made explicit by the researcher) were able to overcome the language barriers preventing them from getting the care they needed through social networking. Friends and family members had helped these women communicate their medical needs to the healthcare staff. These extensive social networks, sometimes spanning multiple generations, were able to provide the women emotional support, assistance adhering to medical regimens recommended by their medical providers, as well as crucial information they needed to access health care services.

Heyman, et al (2009) employed a case study qualitative approach patterned after Menjivar's research to examine undocumented Latino immigrants. The authors were seeking to supplement the existing body of research literature, which, they claimed, was predominantly quantitative in nature. They pointed out that results from previous research targeting undocumented Latino populations had reported low levels of unmet health needs among these groups because undocumented individuals had experienced little difficulty obtaining healthcare services. Heyman et al. considered these results an "apparent conundrum in the quantitative material (that) suggests a need for qualitative research" (p. 6).

The 52 undocumented individuals interviewed by Heyman et al. claimed that they had encountered the following direct and indirect barriers to accessing care: (a) the insufficiency of their finances (the most commonly cited barrier); (b) bureaucratic red tape, such as laws which required them to produce documents proving their citizenship; (c) fear of deportation, and (d) feelings of being perceived by others as having a low social status. According to the authors, these factors have not only negatively affected health access for the study's undocumented participants, but have also led to an under-utilization of preventative services by undocumented individuals (e.g., physical exams and diagnostic services), and to a lack of follow-up treatment for chronic conditions.

Heyman et al.'s results confirmed the claims of a previous quantitative study by Berk & Schur (2001) that found anti-immigration legislation (i.e., Proposition 187 and the 1996 Personal Responsibility and Work Opportunity Reconciliation Act) increased the fear among undocumented Latino immigrants that their lack of documentation might

prevent them from receiving health care. Like Menjivar (2002) and Derose (2000), Heyman et al. also noted the existence of several resilient patterns among the participants that facilitated their access to medical care, such as social networking (resulting in information-learning and confidence-building) and creating community support for their circumstances.

Cristancho, Garces, Peters & Mueller (2008) conducted focus groups in a rural midwestern region of the U.S. to determine the commonly perceived barriers to health care access and use of services among 181 Latino documented and undocumented immigrants. The participants who were undocumented reported that their main barriers to care were: (a) lack of health insurance, (b) high cost of health care services, (c) language-related problems, (d) discrimination and (e) problems with transportation. Cristancho et al.'s findings also highlighted another problem experienced by immigrants living in rural areas, namely the lack of properly trained medical interpreters in their local healthcare systems.

Discussion

The studies reviewed provide empirical evidence that disparities in health care access and utilization of services exist among undocumented Latinos, and also supporting the hypothesis that the true Latino health condition might be worse than it appears. Some of the recurrent themes in the literature about the access to and use of healthcare services of undocumented immigrant women, when compared to their documented counterparts: (a) were more likely to be uninsured, (b) were less likely to have a primary care provider or a usual source of care, (c) used less urgent and emergent care, (d) used less preventive

services, (e) rated their health poor or fair, (f) used social networking to overcome obstacles to obtaining the necessary medical treatment, and (g) expressed a great deal of dissatisfaction with the care they received.

It is clear from the data presented in this article that the preponderance of published research does not adequately address the specific healthcare issues of Latina immigrants (especially the undocumented), and that, in spite of the increasing numbers of Latina immigrants in the U.S., a large gap in the research still exists. The literature discussed in this review contains primarily surveys of health care utilization and access among undocumented Latinos. Not only have many of the earlier studies used surveys with large, national samples, some are at least ten years old (Berk et al, 2000; Hubbell et al., 1991; Ku & Matani, 2001). Though they provide large aggregate data sets, they did not often control for extraneous factors that might affect the validity of the results (e.g., recall bias or uncorroborated self-reports). In some studies, the sample population of Latinos had not been adequately described, nor had a participant's documentation status been explicitly mentioned. Furthermore, even though many Latino groups share the same language, they come from diverse cultural backgrounds, socioeconomic statuses and varying documentation statuses, and should not be regarded as a monolithic group. However, this is precisely how much of the research treats Latino populations.

Most of what is known about the healthcare-seeking practices and utilization of services among undocumented Latina immigrants comes from studies where researchers have used measurement variables to understand health disparities in healthcare access and utilization among this population of immigrants, such as (a) number of physician

visits per year,(b) usual source of care, (c) number of ED visits per year, or (d) tendency to delay seeking appropriate care and using other means to meet her medical needs (e.g., obtaining prescription drugs to quantify). Health and social factors are parameterized into dependent and independent variables using quantitative methods for analysis. In this approach, a person is always seen as an object, rather than as “a creative, generating being who lives embedded in a context of meaning, a being whose actions and understandings form a comprehensible whole” (Benner & Wrubel, 1994, p. 35) Approaches such as these have only partially captured the true nature and reason for healthcare disparities.

Researchers who have studied undocumented individuals have suggested that barriers to access may extend beyond the lack of health insurance, and often include an immigrant’s perception of discrimination and marginalization by those within the healthcare system (Derose, 2000; Garces, Scarinci, Harrison, 2006; Horwitz, Roberts & Warner, 2008; Lauderdale, Wen, Jacobs, Kandula, 2006). This perception, be it accurate or not, may influence a person’s utilization of health services. This could explain the reason behind the decrease use of urgent and emergency care among undocumented immigrants. The literature also showed that immigrants who are both undocumented and uninsured have unique risk profiles. They tend to report higher rates of unmet medical needs and dissatisfaction with the care they receive as compared to their documented counterparts. This suggests that other contextual factors might be at play in influencing the barriers to healthcare services among undocumented Latina immigrants. Thus,

undocumented Latina immigrants are an under-studied population and a critical gap in the literature exist- the need to include an immigrant's voice in the matter.

Qualitative studies with undocumented Latinas are needed to supplement quantitative inquiries, which often fail to capture the human side of a person's struggles in getting care for their medical conditions (Kleinman, Das, & Lock, 1997). Specifically, more qualitative studies that explore the personal experiences of immigrants can help illuminate their barriers to care. In turn, this critical information can be used by policymakers in order to create health and social policies that best frame the issues surrounding access to and quality of care among this vulnerable population (The 2007/2008 Forum on Migration and Health). Healthcare professionals and policymakers need an adequate knowledge of the personal and social factors that may contribute significantly to the poor health outcomes and the health disparities that exist in this patient population.

Implications for Future Research

Even though chronic diseases such as cancer and heart disease are the leading cause of death among Latina immigrants (Aguirre-Molina & Molina, 2003; Winkleby, Kraemer, Ahn & Varady, 1998), researchers have paid little attention to the barriers faced by Latina immigrants with serious chronic illnesses when seeking care. Instead, most of the previous studies with Latina participants have focused on other issues such as reproductive health, substance use and abuse, and sexually transmitted diseases. This suggests a need for new studies which specifically target chronic illness among Latina immigrants (Aguirre-Molina & Molina).

Also, studies focusing principally on Mexican immigrant women are lacking in the research literature. Mexican immigrant women have unique qualities that distinguish them from other Latina immigrant women (Kaestner, Pearson, Keene, Geronimus, 2009). Their modes of socioeconomic incorporation and acculturation into the societal mainstream differ from other Latina immigrants (Kaestner et al). Also, in a study comparing immigrant women from five different Latino subgroups, Freeman & Lethridge-Cejku (2006) found that Mexican immigrant women were: (a) more likely to have less than a high school education, (b) more likely to live in poverty, (c) more likely to lack health care coverage, (d) less likely to have a usual place of health care, and (e) more likely to have an unmet medical need due to cost.

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“No me ponían mucha importancia”:

The Need for Recognition: Experiences of Undocumented Mexican Immigrant Women
with Chronic Illness

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Abstract

Subjective perceptions of mistreatment and discrimination by indigent and immigrant populations increase their barriers to healthcare and have a direct negative impact on their physical and psychological health. Compared with non-Latino women, Mexican immigrant women have higher prevalence of certain chronic diseases and experience more racial discrimination. Their experiences of mistreatment, marginalization and stigmatization could contribute to poor health outcomes, particularly among those with chronic illnesses who require ongoing care. This article presents the findings of a qualitative study that explored the health care-seeking experiences of undocumented Mexican immigrant women (MIW). An interpretive phenomenological study using open-ended, semi-structured interviews, participant observation, and field notes was conducted with 26 uninsured, Mexican immigrants with a chronic illness residing in California. Narratives of study participants revealed that their health care seeking experiences were often characterized by a lack of recognition of their human plight and the devaluation of their personhood. Failure on the part of both healthcare staff and medical providers to recognize the healthcare needs of the women participants was perceived as an obstacle to gaining the care they needed. The findings of this study suggest that both structural and social barriers to care exist for immigrant women. Modifying current health care policies by allowing undocumented immigrants more options to access care could help reduce stigma, reduce suffering, and encourage health professionals to recognize their humanity and their legitimate medical needs.

Key words: perceived discrimination, stigmatization, barriers to healthcare, invisibility, objectification.

Introduction

“They gave me some red pills, supposedly for the infection, and others for the pain. That was the only thing they did because it was an American doctor who treated me, it was a man and he didn’t seem to give me much importance.” Rosa

Stigmatization and perceived discrimination have been shown to contribute to barriers to accessing health care among indigent, minority populations (Derose, 2000; Garces, Scarinci, Harrison, 2006; Horwitz, Roberts & Warner, 2008; Lauderdale, Wen, Jacobs, Kandula, 2006). There is substantial evidence in the literature demonstrating the negative effects of perceived discrimination on physical and mental health (Pascoe & Rischman, 2009). Cancer and heart disease are the leading causes of death among Latina immigrants (Aguirre-Molina & Molina, 2003; Winkleby, Kraemer, Ahn & Varady, 1998). Thus, undocumented Mexican immigrant women (MIW) with chronic illnesses are at heightened risk for poor health outcomes stemming from barriers to care associated with their being stigmatized and marginalized (Derose, Escarce, & Lurie, 2007).

The social processes that create health care access barriers are not well captured by aggregate level data and epidemiological studies. Nonetheless, these processes may play a significant role in increasing social and health inequalities experienced by undocumented, uninsured MIW with chronic illnesses. For this reason, a qualitative approach may be better-suited to exploring the social roots of the access problem.

This article presents the findings of an interpretive phenomenological study that explored the care-seeking experiences of uninsured, undocumented Mexican immigrant women with chronic illnesses in a coastal town in central California. The study explored: (a) the contextual factors influencing their care-seeking experiences (e.g., socio-cultural, personal, and structural factors), and (b) how their lack of health insurance affected their ability to access and obtain necessary medical care.

Chronic Disease and Perceived Discrimination

The three chronic disease categories causing the greatest disparities in health among MIW are: heart disease, diabetes mellitus, and certain cancers of the reproductive and digestive systems (i.e., breast, cervical, liver and stomach cancers) (Ramos, Jurkowski, Gonzalez, & Lawrence, 2010; Vega, Rodriguez, & Gruskin, 2009).

Cardiovascular disease (CVD) is the primary cause of death for all women in the U.S., including MIW (Vega, et al, 2009). Winkleby, Kraemer, Ahn, & Varady (1998) found that Mexican-American women had a higher prevalence of CVD risk factors (e.g., high body mass index, high blood pressure, and low levels of physical activity).

Among MIW, diabetes is the fourth leading cause of death, and the major cause of morbidity among MIW who are 45 years or older (Aguirre-Molina & Molina). The rate of diabetes (10.9%) for MIW is more than twice that of White women (4.9%) (Vega, et al, 2009). MIW who develop diabetes tend to be younger at the time of diagnosis, have poorer glycemic controls, demonstrate more insulin resistance, and experience more complications from the disease (Peralta, et al., 2006).

Breast cancer is the leading cause of cancer-related deaths in this ethnic minority group (Ramos, et al.). Also, MIW have more advanced stages of the disease at initial presentation, with a survival rate that is five years less than their non-Mexican counterparts (Aguirre-Molina & Molina, 2003; Borrayo & Jenkins, 2003; Buki, Jamison, Anderson, & Cuadra; 2007).

Subjective experiences of mistreatment have been documented as a significant social determinant of health (Barnes, Mendes de Leon, Lewis, Bienias, Wilson, & Evans, 2008). Several studies have demonstrated a link between perceived discrimination and negative health outcomes in specific chronic illnesses such as hypertension, obesity and breast cancer among ethnic and racial minority groups in the U.S. (Gyll, Matthews, Bromberger, 2001; Pascoe & Richman, 2009; Ryan, Gee, Laflamme, 2006; Taylor et al., 2007). Latinos have reported experiencing more perceived racial discrimination in the health care setting compared to non-Latino whites (Johnson, Saha, Arbelaez, Beach & Cooper, 2004; Lillie-Blanton, Brodie, Rowland, Altman, & MacIntosh, 2000; Lauderdale, et al., 2006). Among Latina immigrants, chronic psychosocial stress resulting from perceived discrimination has been shown to increase cardiovascular disease risk. Specifically, investigators found a strong direct association between Latinas' self-reported discrimination and their fasting blood glucose levels (McClure, et al, 2010).

Researchers and policymakers have given inadequate attention to the extraordinary barriers to care that may contribute to increased morbidity and mortality in this vulnerable population. Researchers frequently attribute the barriers to "behavioral and idiosyncratic factors" (Vargas Bustamente, et al., 2010, p.8). Relatively few studies

have examined healthcare access and utilization of care by undocumented MIW. Most studies conducted in the area of health inequalities among undocumented MIW have used demographic or large epidemiological surveys. The consensus among these studies is that undocumented immigrant women used less healthcare services, rated their health poor or fair, and expressed a great deal of dissatisfaction with the care they received. This suggests a need for qualitative studies to explore the nature of this dissatisfaction and how it may contribute to access barriers. A few qualitative studies have focused on undocumented immigrants (Derose, 2000; McGuire & Georges, 2003; Menjivar, 2002). However, they either did not include women, or they were not specific to women with chronic illnesses. To our knowledge, there are no previous studies examining experiences of undocumented women with chronic illnesses seeking care in the healthcare safety net system. Therefore, this study fills a critical gap in the literature in this area.

Methods and Design

This interpretive phenomenological (IP) study was grounded in the philosophy of Heidegger (1962), as interpreted by Dreyfus (1991), and as applied in nursing through the work of Benner et al (Benner, 1994; Benner & Wrubel, 1989). The goal of research informed by IP is to understand the world of the participants from their vantage point, appreciating the cultural and social influences that have shaped their experiences of the world (Heidegger). The basic premise of IP is that human beings are self-interpreting, relational beings who are always already *thrown* into a pre-existing world (Heidegger). The state in which we find ourselves in the world is what Heidegger called *thrownness*

(or situatedness). The possibilities available in each person's life are a function of his or her being *thrown* into a particular culture, family or historical world (Benner, 1994). This contrasts with the Western ideal of individuals as radically free to choose their identities and ways of being in the world.

In the phenomenological tradition, the researcher interprets personal narratives, field notes and participant observation as data sources to make explicit socially embedded meanings from the unarticulated, everyday lived experiences of the participants. IP is well-suited for analyzing the lived experiences of undocumented, Mexican immigrant women living with a chronic illness because it facilitates analysis of everyday social discourse to reveal concerns, meanings and taken-for-granted assumptions of everydayness of the participants (Heidegger).

Data Collection

The Free Clinic

The study was conducted at a clinic conveniently located in the center of a small, coastal town in Central California. It has served the uninsured, working poor of the local community for 15 years. Staffed by a cadre of volunteer doctors, nurses, and lay persons, the clinic provides patients ambulatory medical care, laboratory and imaging services, and a select listing of prescription medications, all at no cost. About 40 to 50 patients queue up in front of the clinic once a week. Many come as early as four to five hours before the clinic opens, usually to be seen for nonemergency illnesses. During clinic days, the person in charge of patient traffic, Federica, opens the clinic doors a few

minutes after 5 p.m., and begins to pass out admission tokens. Patients sometimes endure exposure to cold, wind and rain for hours in order to receive a much-coveted token. Once the tokens are gone, those who came late and are unfortunate enough not to receive one are turned away and advised to return the following week, regardless of the urgency of their need.

The Women

Criteria for inclusion in the study required that participants: (a) lack legal documentation (the participant must have entered the U.S. illegally or overstayed their visas); (b) have a diagnosis of a chronic illness (using the Center for Disease Control's definition of a prolonged illness, lasting three months or more, continues indefinitely, recurrent and generally cannot be prevented by vaccines or cured by medication) (CDC, 2000); (c) lacked full-scope health insurance (the participant must not have any private or public insurance; but she may be able to qualify for temporary state health insurance (e.g. for treatment of tuberculosis, management of pregnancy, etc)); (d) of Mexican origin (born and raised in any of the provinces of Mexico; and (e) be a female at least 18 years old.

Twenty-six immigrant Mexican women (three Zapotecs, one Mayan, and 17 non-indigenous Mexicans) were recruited from a free clinic located in a small town in central California. A small sample of Triquis (n = 1) and Mixtecas (n = 4) were recruited from a farm-worker community situated about 50 miles from the coast. For a description of study participants, see Table 2. A total of 29 interviews were conducted. Three key

informants were interviewed twice in order to seek more information and to confirm the meaning of narratives.

This research was approved by the Committee on Human Research, the Institutional Research Board of the University of California, San Francisco. Study participants were recruited using word of mouth and snowballing methods. Verbal consents were used because many participants were pre-literate. In lieu of a signed informed consent, an IRB-approved study information sheet was used to further minimize identifiers. Study participants were paid \$15 for an hour of their time.

Data were collected by the first author using ethnographic methods, including interviews, participant observation and field notes. A total of 29 audiotaped interviews were conducted with 26 participants using an open-ended, semi-structured guide. Topics discussed included: (a) what the participants' lives were like before coming to the U.S., and what their lives were like at present, (b) what their illnesses were, and what they needed to do to manage them, (c) what they felt was the hardest thing about having to live with their chronic illness, (d) where they went for medical care, (e) how they paid for the treatment for their illness (including all necessary medications), and (f) whether or not they had ever been treated poorly by healthcare providers and/or ancillary staff because they were uninsured. To maintain confidentiality, fictitious names were used in the following accounts.

All interviews were conducted by the first author (partially fluent in Spanish) and also an interpreter who was both multilingual (i.e., completely fluent in both Spanish and English--also either Triqui, Zapotec or Mixtec, if necessary) and multicultural to facilitate

mutual understanding and provide additional interpretation when needed. The fieldwork took place over the course of one year. The first author also had opportunities to work and observe at the clinic for three years prior to the start of the study (providing medical care as a volunteer nurse practitioner), adding to her understanding of the context.

Data Analysis

Data collection and analysis occurred simultaneously, and were iterative in nature. Questions were added to the initial interview guide as participants expressed new themes during the course of data gathering. The taped interviews were transcribed verbatim, and subsequently translated into English by multilingual and multicultural translators. The transcribed, translated narratives were entered into a qualitative data management software, *Atlas ti*, to assist with data organization and coding. Each narrative was read multiple times to gain a holistic understanding of the participants' experiences and to look for "incongruities, puzzlements, and unifying repeated concerns" (Benner, 1994, p.113). Interpretation of the narratives was done in hermeneutic phenomenological tradition, which involved three levels of analysis: exemplars, paradigm cases, and thematic analysis.

Thematic analysis consisted of identifying specific segments of the texts, and coding and grouping them into recurrent themes. The first author extracted exemplars (smaller narratives or portions of narratives) from the text to illustrate each identified theme or pattern of meaning, and developed a series of paradigm cases (individual stories of a select group of participants whose lives reflect the concerns, practices and circumstances experienced by the women, in general). Paradigm cases, as described by

Benner, are “strong instances of concerns or ways of being in the world” (p.113).

Paradigm cases allow an insider’s look into the participants’ lives, with the goal of hearing and understanding their voices.

Methodological Rigor

Triangulation, prolonged engagement, thick description, member checks and reflexivity were used to enhance validity (Creswell, 2007; Whitemore, Chase, & Mandle, 2001). As part of triangulation, multiple methods and data collection approaches were used to confirm the information gathered (Guba, 1981). Consultations with interpreters and several participants provided member-checking to ensure that the meaning ascribed to the narratives indeed captured participants’ experiences (Guba). From a Heideggerian stance, member checking means understanding the world of the participants from their vantage point, and being able to convey, respectfully, their “taken-for-granted meanings, practices, habits, skills, and concerns” (Benner, 1994, p. xviii). The researcher has succeeded in making a valid interpretation, according to Dreyfus (1991), when she is able to put into words what the participant has always known, but did not have the words to say. Thick description involved preparing detailed accounts of situations, painting a vivid picture of events and persons within a societal context. Subsequently, various portions of the raw narrative data were discussed with an interpretive group that met biweekly and with a dissertation committee made up of qualitative and quantitative researchers, with extensive experience working among ethnic minority and immigrant populations. Prolonged engagement entails spending sufficient time in the field to allow the researcher to go beyond their preconceived understanding of

the phenomenon of interest (Cohen & Crabtree, 2006). The time spent engaged in the phenomenon should adequately facilitate familiarity to the degree that the researcher is able to discern inconsistencies in the data. Practicing reflexivity throughout each step of the data collection and analysis processes is important because the researcher is the instrument through which the phenomenon is revealed (Lincoln & Guba, 2003). Reflexivity enhances the researcher's ability to keep separate her own perceptions and biases from the meanings held by the participants about their own lives, illnesses, and experiences (Lincoln & Guba).

Findings

Participant: "In reality, you do feel hurt because even though you could be dying, they ignore you, right? If with our disease (i.e., diabetes), we struggle to breathe, we still get confronted (i.e., by the hospital staff) with the problem of not having papers, or not having this or the other, and then they will not give us medical attention."

Listening to the voices of those who are suffering is one of the most difficult tasks human beings ever have to do; yet it is something that must be done, regardless of the discomfort it may cause (Frank, 1995). As Frank observes, "the voices of the ill are easy to ignore because these voices are often faltering in tone and mixed in messages." (p. 25). The voices of the women in this qualitative study reflected the profound need they felt to be *recognized* by those with whom they interacted during their care-seeking processes. As the title of this article conveys, most of these women felt that they were not given much importance (*no me ponían mucha importancia*) during such experiences. The

meaning of *recognition* intended here is well-defined by Benjamin (1988) as “to affirm, validate, acknowledge, know, accept, understand, empathize, take in, tolerate, appreciate, see, identify with, find familiar...love” (pp.15-16). While it may be unrealistic to consider that health care practitioners would “love” all their patients, the other aspects of Benjamin’s definition are characteristic of excellent caring practitioners, and their lack is associated with a disengaged style of practice that is destructive and even dangerous. (Benner, 1994)

The Need for Recognition

In the following section, we draw from the narratives of Mexican immigrant women to illustrate how the lack of recognition they experienced affected their care-seeking practices. The failure to recognize these women for their equal value was in some instances manifested by: (a) treating them as invisible by ignoring their legitimate medical complaints, (b) not recognizing their solicitations for help, and (c) by providing them with what they experienced as a kind of objectified, disengaged care. In contrast, certain care practices were received by participants in a more favorable light because they were experienced as being forms of recognition.

Lack of Recognition as Invisibility

The felt health needs of the women in this study were not always recognized by the healthcare staff for a variety of reasons, as is illustrated by Rosa’s story. Rosa, a 46 year old participant with swarthy skin weathered by years spent laboring under the hot sun, looked older than her age. Like most of the participants, she had crossed the border

illegally. Rosa had made the precarious journey with two daughters, leaving seven other children behind in Mexico. She had already been afflicted with tuberculosis before she arrived in the U.S. Rosa's tuberculosis infection had resulted in severe renal scarring, causing sudden sharp pains that came upon her intermittently, and often left her totally incapacitated. Her bouts with chronic pain had often led her to seek relief at the emergency department of the local hospital (ED). One time, Rosa developed excruciating flank pain while working as a hotel maid. One of her family members took her to the ED. Unfortunately for Rosa, the attending ED physician did not recognize the severity of her symptoms, and dismissed her symptoms as the result of a simple urinary tract infection, failing to do a complete work-up and sending her home with a prescription for antibiotics. Rosa recounted her experience:

Every day there was more pain, more stinging when urinating and back pain, back pain and then it would rush this way and towards the pelvis, and I felt very bad.

Once I got to the hospital they didn't do any analysis, nothing, he said they would do some analysis, but they didn't do anything other than a urine analysis... Then he said "well with these pills and you have a lot of infections..." And he gave me some pills...and it didn't do anything because on the contrary there was more pain and because of that I still resisted another few days...and then they took me to the hospital, but they only sent me back home.

Rosa continued, "that was the only thing they did because it was an American doctor who treated me, it was a man and *he didn't seem to give me much importance...*" In Rosa's view, the "American" physician dismissed her as somehow undeserving and

unimportant, suggesting that she experienced his actions as reflecting her differentness from him, and saw this differentness as the reason for his lack of engagement.

Rosa's pain only worsened; yet she endured it for eight more days before going back to the hospital. She did not say why she had waited so long before seeking help again, especially when the pills she had been prescribed had failed to relieve her pain. It might have been because she had the utmost trust in her doctors: "because they are specialist, and they know what and why is the cause of where one is hurting." But it appears that her sense of not being of much importance might also have been a factor. Not wanting to again experience minimization of her pain, she waited until she was near the breaking point. Going to the ED again was an act of self-assertion on Rosa's part, as well as an appeal to be recognized in her distress. She had waited until she was in a desperate state before going back. Hoping that, perhaps this time, the doctor would recognize her suffering and take her pain seriously, she reported that this time:

It was good because the doctors, at least when I entered, there were a lot of people there but they gave me preference because I was sweating with pain, and they attended to me first, they left the rest of those seated there. They saw to me first and then I'm telling ... well, I don't know if it's because they saw me so bad off...

Rosa was a bit apologetic when she described her momentary loss of control over her emotions and why she was "almost crying" while in the emergency room:

Then I couldn't tolerate it anymore, I resisted and eight days later I had to go back to the hospital. I went to the hospital because I couldn't handle the pains and it was then that they treated me like an emergency and they told me that I looked all sweaty with pain, sweating and desperate like almost crying also because I was already so desperate. Because I felt like something was going to come out of my parts and I would tell them I couldn't handle it anymore.

Rosa "resisted" returning to an unwelcoming ED until she experienced her pain as threatening to open a rift in her intact body. This was a situation of "desperation" that called for the desperate measure of returning to a place where she had been dismissed as unimportant and unworthy of further examination. She experienced relief at finally being "treated like an emergency" by having her pain recognized as authentic and worthy of intervention.

While it is tempting to characterize caregivers as unfeeling, the ED setting is fraught with time pressures and the ability to quickly and effectively communicate about one's problems renders some patients more likely to be "seen." (Malone, 1998). In this setting, immigrant women's inability to communicate in English, or their omission of certain culturally-known, facial and bodily expressions that communicate need (Honneth & Margalit, 2001) disadvantages them. Among other things, the level of recognition conferred on a person is dependent on the appropriateness of their expressive bodily gestures; something gained, according to Honneth & Margalit, "only with the help of media that, by virtue of their symbiotic structure, are modeled on the expressive bodily gestures with which human beings confirm their social validity to one another" (p.119).

Rosa spoke of a friend from El Salvador who “just from getting very angry, had a stroke.” In Rosa’s understanding, severe emotions like anger or fear can cause serious physical ramifications. This would explain why she attempted to control her emotions when she was in pain, rather than visibly expressing them. However, her guarded stance and expressed gestures to demonstrate pain on the first visit were unfamiliar to those who needed to recognize them for what they really were--pleas for someone to help relieve her of her pain.

Unrecognized Solicitation

Domination and submission can result if the necessary tension between self-assertion and mutual recognition in relationships is not maintained (Benjamin, 1988). A breakdown in this balance was reflected in the experiences of the immigrant women in the study, where instead of recognition, the relationships between the women and some members of the healthcare safety net system deteriorated into ones of domination (by healthcare providers) and submission (by the women). This is illustrated below in the interactions between the clinic gatekeeper and the clinic patients.

The clinic gatekeeper. Federica, the clinic’s gatekeeper, was a prominent figure in the women’s narratives. She had been a stumbling block for many of the frequent users of the clinic in getting the care they both wanted and needed. She embodied the many obstacles and barriers that these women faced as they sought care from the safety net system for their chronic illness. Federica is a Latina woman who, along with her husband, had been volunteering faithfully every week at the free clinic for over eight

years. One could say that eight years is sufficient time for Federica to have endeared herself to the clinic patients. However, this has not been the case here. In fact, most of the patients I interviewed expressed feelings of intense animosity towards her. They complained that she treated them with great contempt, often berating them or yelling at them in front of others. One of the women I interviewed called Federica a “despot” -- “like she feels like she is better than the rest, she doesn’t care the way she treats others.” Another interviewee became vitriolic, expressing intense anger toward Federica: “she is very harsh...the same lady (Federica) said to me “we don’t see people with diabetes here! Go somewhere else...look for another place”. Federica was notorious for having sent patients home for no apparent reason, even though they had stood in line for hours hoping to be seen for their medical ailment. “I was there (in line) for three hours, and it was raining very hard, I told her I was there for my lab results [and] she said ‘No, they can’t see you today...’ she yells at me in front of all those people and I had to go back home. Can you imagine how I felt?” Another participant regarded Federica with great disdain— “she steps on us, so she can later spit on us.” “She is always there”, another complained, “She asks what the reason for the visit is and she decides if you go in or not. And then in front of all the people she yells at you and says ‘No, we can’t see you here.’”

The free clinic was dependent on volunteers, like Federica, in order to function on a very limited budget. Operating with meager resources, Federica was charged with the onerous task of crowd-control at the clinic, including dealing with patient complaints and requests. Since no one else at the free clinic with triage experience seemed to want the job, Federica, although not a health professional, was left to develop her own brand

of “triage.” Her approach to the sheer volume of unmet need was to appear to be cold and ruthless at times, especially to those she turned away for not presenting what she considered to be “an emergency.”

My sister had an ingrown toenail and her toe was purple. She couldn’t even walk - the lady (Federica, “the gatekeeper”) told her ‘that is not an emergency--you want to use this clinic as your own (personal) private clinic,’ she said, and seeing that her toe was big and purple and my sister said, ‘if I didn’t have a need, I wouldn’t have come.’

This patient came that night knowing that she would first have to plead with Federica to allow her to see a provider (like the others who were waiting to enter the clinic). The visit to the free clinic was, in itself, a plea for recognition. Inasmuch as the engaged body is constantly involved in meaningful experiences, it is also always being *solicited* by the situation (Merleau-Ponty, 1962), as a glove solicits someone to slip his or her hand inside it (Doolittle, 1994). The above scenario illustrated Federica’s failure to recognize and respond to the solicitation of this patient’s urgent condition. Perhaps, Federica’s preoccupation with the task of maintaining order at the clinic’s entrance, or her lack of medical training contributed to her inability to appreciate the gravity of the patient’s dilemma. Federica reacted by accusing the patient instead of taking advantage of the free medical care the clinic provided. Though this woman’s (i.e., the participant’s sister) demands, like those of many other patients there, may have seemed low priority to the clinic staff, this response ignored the patient as a suffering human being.

Being singled out and paraded in front of their peers was another affront to human dignity patients often suffered at the hands of the gatekeeper:

They ask us to form a line, when it gets long she divides it into three: diabetic here, normal here and new here, then, it happens that you say, hey, I came after this person, but when you see, you are suddenly last, and the last ones who got there is first and the one who came first is now last. There is chaos in that lady.

Those who have been waiting the longest find themselves suddenly at the end of the line. Federica passes out the tokens and when they run out, those remaining in line are told to sign their names and return the following week, even though they came earlier than some who received tokens. But the decisions about how this process worked were experienced by the would-be patients as arbitrary. One way Federica wielded her authority was by changing the rules in how she did triage. By standing in line in front of the free clinic, openly visible for others to see, the patients were soliciting others to recognize them as people in need. However, stigmatization, rather than recognition and response, was what had ensued, and those who were unsuccessful in securing Federica's favor felt unfairly labeled and categorized as "other."

Imelda's story offers another example illustrating the ramifications of a breakdown between self-assertion and mutual recognition. Imelda, 56, had salt and pepper hair and dark-rimmed glasses. Imelda spoke very forthright about how she was treated unfairly, not getting services at the free clinic on several occasions because Federica had denied her entrance. When I spoke with her, she had been coming to the

clinic for over a year for her diabetes. However, one evening she came seeking help for a completely different problem—an injured finger:

I had hurt my finger, a door slammed on my finger. It was a big bruise. I thought that I had broken the bone, but it was not broken. The finger swelled up, and the blood and all was here, so I went to show the lady (i.e., Federica), and she ignored me.

Hoping to gain entrance into the clinic to get treatment for her severely bruised finger, Imelda reported to Federica that the doctor had asked her to return for a four-week follow-up visit for her diabetes. But, Federica merely ignored her. Imelda then resorted to an act of self-assertion as a plea for recognition. She broke protocol, and entered the clinic without permission to plead her case to someone having more authority than Federica (or, perhaps more compassion). She explained to the interviewer that she had been prompted by her daughters to aggressively seek help because she feared losing her entire arm, due to her diabetes: “‘Go Mama to the doctor’, my daughter suggested, and it’s just that I didn’t want to let it get worse and possibly have to cut off my arm.”

To Imelda’s disappointment, however, even after breaking through into the clinic itself, she did not receive the care she desperately wanted because the providers had not yet arrived. There was no one else to appeal to that early in the evening. Instead, Imelda reported that one of the clinic’s staff had said to another person, “This does not require care, right?” When the other person replied, “no,” Imelda said sadly, “I was disappointed...that is what I mean--sometimes *they ignore me.*” What Imelda experienced as a threat that could result in permanent loss of her limb was dismissed as

unworthy of attention. The possibly overworked and under-educated staff failed to heed the *solicitation* to attend to Imelda as a person, which might have permitted them to understand how she perceived the threat of her injured finger.

Imelda related a similar experience in a local Medicaid office:

I had a black eye –my husband hit me, so I went to see if a doctor would see me—I went in and the lady asked me: “Do you have U.S. born children here?” I responded correctly. I told her the truth. I did not say, “yes,” or “no,” I said, “No, I do not have U.S. born children here.” I told her, “My children recently arrived to the U.S.” Then the lady said, “Well, we are done.” She was done with her services, and no further attention. She said, “I am done with my questions. So, I just left disappointed. *I think that is an injustice.*

On this occasion, Imelda had come with a visible need (a black eye), wanting to obtain the means to get medical attention for it, but had instead felt dismissed, slighted and rejected by the Medicaid worker. Both at the clinic and the Medicaid office, Imelda’s experience was that of feeling morally violated for doing the right thing (e.g., telling the truth). The Medicaid worker’s questions put Imelda into a no-win position: to obtain insurance that would allow her to receive care for her injuries, she would have to answer falsely, assuming an identity of someone “visible” (to the system) . To tell the truth, despite her obvious, visible need for care, meant being denied that care. Imelda considered this an injustice, perhaps because she expected things to be better in the U.S.: “in Mexico you have to have the money first before they see you, here is a thousand times better.”

The Lack of Recognition and Objectification

Another participant, Alondra, 52 years old at the time of the interview, came to the U.S. when she was in her early twenties. She said she had come at a time when immigration was lax, allowed by *la migra* (the border patrol) to walk across the border without any hassles. Although Alondra had begun her journey to the U.S. accompanied by her aunt and sister-in-laws, soon thereafter she somehow found herself living here alone, working for a malevolent woman who owned a restaurant. Alondra's job at the restaurant had been to make food for the fieldworkers, though she said the woman never paid her for her work. Alondra was also not allowed to communicate with her family. The woman who owned the restaurant wanted Alondra to prostitute herself to the men who frequented it. When she refused, the woman would beat her, give her spoiled food and taunt her by saying, "You will never get married, you are a *mosca muerta*" (someone pretending to be moral when in fact she is not).

However, Alondra eventually married. In fact, we conducted the interview in her bedroom while her four children and three grandchildren gathered in their small living room enjoying a pizza together. She occasionally got up from the bed where we were sitting to attend to a week-old infant, the youngest of her grandchildren. She swaddled her granddaughter in a soft blanket, rather expertly and with great ease, making it obvious that she had done this many times before. This scene was in sharp contrast to the inauspicious beginning to Alondra's life here in America.

After she had escaped from the clutches of the tyrannical woman with the restaurant, Alondra found herself in similar situations many times over at the hands of

other ill-meaning people (e.g., being falsely imprisoned, and physically and psychologically abused) until she finally met her current husband.

Alondra's fortitude is what had helped her to overcome the dehumanizing circumstances in her life--perhaps the same fortitude that had enabled her to tolerate the circumstances surrounding her cholecystectomy, another rough chapter in her life that she disclosed during the interview. She related a story about the time a particular surgeon had failed to provide her with anesthesia, performing a procedure without warning her about the degree of discomfort it would cause:

After the (gall bladder) surgery, the doctor said I had more gall stones, "do you want to keep them or we can take them out, but this time we are going in through the mouth, they will put a hose in and pull up the stones, will you be able to handle it," he said. So I thought to myself, if this is the only time that they will give me MediCal and the pain continues, so I thought I could handle it. I was all brave and said "yes," but I didn't know what they were going to do to me when they put me face down and on my sutures. It was going to pull the stones up he said and that it was going to go inside and pull it up through the mouth, I felt all the pain because they didn't give me any anesthesia...I felt everything.

When the physician's expressed concern about whether Alondra would be able to "handle it," he seemed disingenuous (and maybe a bit patronizing). The surgeon in this story was obligated to give Alondra accurate information that would enable her to determine how she wanted to participate in her healing (Kestenbaum, 1982). Medical

providers are warned to guard against the “persuasion that becomes coercion because of the subtle slanting of evidence or incomplete disclosure” (p.163). Alondra agreed to have the procedure because she realized that she might not have medical coverage later and the remaining stones might have caused her more pain in the future. “I was all brave”, she said, willing to face a procedure with total trust that her surgeon would not subject her to something she could not handle. Alondra experienced the physician’s remarks as describing something relatively innocuous (“it will be like putting a hose to pull up the stones”). Perhaps she did not completely understand the doctor’s description of what she agreed to undergo, but conducting such a procedure in the absence of proper preparation constitutes inhumaneness of treatment (Frank, 2007). Throughout the procedure, Alondra had felt extremely vulnerable, lying face down on her freshly-sutured abdomen and being mute because of her inability to express herself in English. She had been subjected not only to the pain that accompanied the procedure, but also to the indignity of being placed in a position of such vulnerability. Perhaps in his haste to “process” Alondra through in the most efficient and least costly way possible, the physician had overlooked giving her anesthesia. Alondra experienced the procedure as an unexpected violation of her trust and confidence, in which her bravery was exploited but not recognized in human terms.

Practices of Recognition

As well-illustrated above, the tension in the relationships between the Latina participants and those with whom they came in contact while seeking healthcare had usually broken down. However, there were a few instances in the narratives that spoke of

times where mutual recognition had been preserved, where the woman experienced herself as being considered as a unique human being with a value equal to her providers, and her medical complaints were treated as being legitimate and worthy of care.

Concern as recognition. Lupe was a 42 year old participant who, leaving her three children behind in Mexico, came to the U.S. to escape an abusive husband. When interviewed, she had not seen her children for 23 years. Unlike other women interviewed, Lupe was alone in the United States, having no family to speak of who lived in this country. She was sharing a three bedroom apartment with total strangers. Lupe listed a myriad of health problems, but the worst of them was her proclivity to have bloody emesis at the slightest provocation:

I was seen for something very bad in my lungs and I vomited blood, blood I vomited, I would get agitated just a little bit and blood...at night, when I sleep and I had to grab like this... I was bleeding and the doctor said you do not have anything or we cannot do anything for you, but they never did anything for me...they would say, you can go home you are fine that's all...they ask for insurance, if you don't have it, it is like they don't give you much importance.

She made frequent visits to the ED, always being told she did not have a medical problem, promptly being sent home each time. She felt that the ED doctors judged her, not according to her inherent value, but by whether or not she had medical insurance:

I went to the doctors...they said they could not operate on me because I did not have insurance, and they did not want to...until I met one doctor that I believe had

pity on me, and he said that he was a private practice doctor...he insisted so much that he would do the surgery...he said, “do you have work insurance?” “No, I don’t”-- “Look,” he said, “I am going to help you with what you have, one day you are going to have a hemorrhage... and you’re going to bleed to death. You are going to go to my clinic and all you are going to pay is for the anesthesia.”

While the nature of this study does not permit us to evaluate the “true” nature of Lupe’s clinical problem, the fact that a physician eventually sought to operate despite her lack of insurance coverage suggests that her problems may have been more than psychosomatic in nature. Whatever the clinical “reality,” this scenario illustrates the significant link between recognition practices and *concern*. Caring is a way of being involved in the world by having people (and states of affairs) matter to us (Heidegger, 1962). Heidegger refers to the form of caring for people as *solicitude*. The physician demonstrated solicitude by offering his services without expecting compensation. .

Relief from pain as recognition. Isabel, a 62 year old participant, told a story about a wound she had “that you could fit your finger in” from an animal bite. Despite her attempts to nurse the wound with home remedies, the pain became so severe that she said “I could not tolerate, you could not tolerate it. I would scream and all.” Like several other women in the study, she had gone to the ED several times but, she said “it was always ‘you’re ok, your pimple looks like an abscess, we won’t know until it pops.’”

One evening, however, she went again to be seen for her wound. Unlike her previous visits to the ED, this one was different:

I kept going back, but nothing...until I don't know what happened I came across a doctor who is Hindu and he asked me "what's wrong?" and I told him, "I came for you to see my foot, but they don't want to see me--they said I'm okay, that I'm okay." Oh, no, he immediately sent a nurse to wash my foot and to soak it in hot water. She told the doctor, "doctor," making a face, she told him "don't touch it with your hands." She made me cry that time, because I said, "well I'm not rotting--I don't have a contagious disease." The doctor got mad and scolded them because they did not want to see me.

Isabel's bold rebuttal to the repugnance expressed by the nursing assistant towards her was a form of self-assertion. She refused to be treated as infectious or as some kind of carrion, but rather as a living, human being. She felt it was significant to mention that this particular doctor was "Hindu." As with the story above about the doctor who was "American" and dismissive, this reference suggests that in this case, Isabel saw the doctor's "otherness" as perhaps accounting for the concern he showed. Unlike the other times she had sought care, this doctor inquired about her particular problem, and the reason for her visit to the ED. Secondly, he validated her medical complaint as legitimate. Then, he immediately sent for a nurse to attend to her-- to wash her feet. Finally, he defended her by scolding the nursing assistant for treating her with contempt-- recognizing and publicly acknowledging the reality of her pain and need for medical care.

Discussion

Recognition is a central element of human existence (Benjamin, 1988). Our identities as human beings, according to Taylor (1991), are formed in a dialogical

relationship with others. Taylor argues that our identities depend on the recognition that is either given or withheld by others. Therefore, when recognition is denied, or an individual refuses to acknowledge the equal value of another, the identity of the other person becomes compromised (Taylor). Benjamin supports Taylor's thesis that tension must exist between self-assertion and mutual recognition in order to allow the self and the other to relate as equals.

The denial of recognition was a prominent theme articulated by the immigrant women in their narratives in this qualitative study. A breakdown in the necessary tension between self-assertion and mutual recognition appeared to have shaped medical encounters that were experienced by the women as demoralizing, dehumanizing, and unjust. The immigrant women wanted to be recognized for the most fundamental of all needs--to be recognized as human beings who had equal value, with concerns that were worthy of the attention of others.

The opprobrium repeatedly expressed by healthcare staff and medical providers toward these women was experienced by the Latinas as a devaluation of their personhood that was based on their status as uninsured and "other." Malone (1998) had similar findings in her study of homeless individuals who were "heavy users" (HU) or frequented EDs. She found that the needs of the HUs were also often rendered invisible by the healthcare staff, and that the only way they showed up as needing care was by giving evidence of a medically "fixable" problem. In this study, the women's needs became recognizable to the staff only when they displayed evidence of extreme distress, or being at a near breaking point. The women's limited proficiency in English and lack of cultural

knowledge about how to express their needs in facial and bodily gestures consistent with those understood by providers may have also contributed to their invisibility (and to their needs going unmet). Frojd, Lampic, Larsson, Birgegard, & von Essen (2007) identified that medical providers rely on a variety of patient cues, including body language and facial expressions, as being an important part of their therapeutic interaction with their patients. Shim (2010) proposed a similar concept she labeled, “cultural health capital (CHC)” as the particular “repertoire of cultural skills, verbal and nonverbal competencies, and interactional styles that can influence healthcare interactions” between patients and providers” (p. 2). Patients who are able to effectively capitalize on the CHC they bring to the medical encounter reap more care-related benefits than those who cannot (Shim). In the case of the MIW, their lack of sophistication in communicating their medical needs in forms recognizable to healthcare providers or their lack of “cultural agility to flexibly present themselves in varying ways” (Shim, p.11) proved to be a detriment to their receipt of optimal care.

Derose’s (2000) findings confirmed the results of this study, in that the medical needs of the immigrant women studied went unmet when they could not communicate effectively with their providers. However, it is important to note that Tang and Anderson (1999) found that the ability of patients with chronic illnesses to communicate with their medical providers in the same language did not guarantee a respectful and “equal relationship” (p. 88).

Another breakdown in mutual recognition came in the form of the missing elements of trust, mutual respect and connectedness in the healing relationship between

some of the providers and the immigrant women. Previous studies have also found that trust was a key element to effective communication when working with marginalized populations (Fox & Chesla, 2008; Leutwyler, 2009; Malone, 1998; Villena & Chesla, 2010). In their study of women suffering from chronic illnesses, Fox & Chesla (2008) found that the feeling of connectedness with their healthcare providers was a profound need expressed by the women. This connectedness was characterized by “a sense of equality, cooperation, negotiation, and shared decision-making” (p. 116). Malone (1998) found that patients who mistrusted their providers often engaged in “scams” to get their health needs met. Among disadvantaged patients who have structural barriers to health care, trust between a patient and her physician was associated with improved opportunities for having her medical needs met (Mollborn, Stepanikova, & Cook, 2005).

Objectification and disengagement were the outcomes when a reciprocal relationship of trust and respect between the women and the medical providers in this study were lacking. When the medical providers assumed a “clinical gaze” (as described by Foucault [1975]), they reduced the participants to being a mere collections of signs and symptoms, rather than as human beings in need of genuine care (Benner, 2001). Benner noted that when providers assumed a disengaged stance, “the other shows up as wholly other with no common humanity” (p.57). Malone (1998) spoke of an *objectifying exclusion* in her study that resulted when providers denied, withheld or ignored the needs of HUs. In this study, objectification blinded the providers to the women’s human solicitations, thus rendering them unable to recognize these patients’ medical needs.

Women experiencing this denial of recognition resorted to various strategies, including breaching the rules, in the attempt to feel cared for. Often, the systems they encountered required them to sacrifice their honesty in order to obtain care, thus creating no-win situations. Some women responded by becoming more submissive, others by bold self-assertion, or persistence in health care-seeking. The women felt devalued when they perceived that their solicitations to be cared for were overlooked and not regarded as significant. Asian American women in Johnson, Bottorff, Browne, Grewal, Hilton, & Clarke's (2004) study responded similarly when their felt medical needs went unmet by their healthcare provider. Many attempted to "fit in" and diminished their external actions by being quiet or not demanding that their needs be met; while others invoked their rights for more equitable treatment.

Recognition practices set up the possibility of self-assertion, and are central to caring because it is in caring that connection and mutual recognition are experienced (Benner, 1994b). Caring practices allow people to be seen and heard, and are a major component of what it means to be fully human (Benner). According to Benner, these practices are too often "invisible and devalued" in our public discourse (p. 43). Studies among Latinas have found an association between healthcare utilization and perceptions of disrespect or unfair treatment (Blanchard & Lurie, 2004; Johnson, Saha, et al. 2004; Lauderdale et al., 2006; Horwitz et al., 2008). Those who had subjective perceptions of discrimination were reluctant to seek care, or delayed seeking it (Derose et al., 2007). Whereas many of the immigrant women in this study were turned away, or had their health problems trivialized, all described having persisted in their attempts to receive the

desired care, regardless of the poor treatment they received. The results of this study suggest that the barrier to obtaining care for these women may lie, not in their reluctance to seek care as a response to feeling discriminated or stigmatized, but, rather in the inability of healthcare staff and providers to recognize and legitimize their medical problems when they do seek care. This is not to suggest that the women's experiences correlate with clinical diagnoses in all instances; this study was not designed to confirm clinical diagnoses, but to study experiences of care seeking. However, in all cases, these women are at higher risk due to their history of chronic illness. Insufficient appreciation of their need for accurate assessment, care and reassurance may result in unnecessary visits, misdiagnoses, or worsening of untreated conditions. This is true for all patients, not only undocumented Latina women. However, the situation for them is exacerbated by their lack of language and cultural skills, lack of other resources, and their perceived "otherness" as undocumented immigrants.

Taylor (1989) posits that a person's concept of self is defined by the way things have significance for that person. The self is defined as it moves in a certain "moral space" of questions as it seeks and finds "an orientation to the good" (p. 34). The lack of recognition these undocumented immigrant women felt when seeking healthcare might well go beyond issues surrounding the barriers to healthcare they faced, to barriers to establishing social identity. The fundamental need expressed by all these women was the desire to be recognized simply, and wholly, as being *human*. For this reason, narratives and ethnographies of vulnerable and marginalized populations, like those found in this study, are crucial to understanding the root of the access problem.

Strengths and Limitations

The findings presented here should be considered in the context of the limitations inherent in the study's design. Study results may have been biased in unknown ways by the use of a small sample of undocumented immigrants who were all Mexicans residing in the same town. The sample of immigrant women who participated may not be representative of the population of undocumented, Latinas with chronic illness. Recruiting a more heterogeneous immigrant sample (e.g., including both documented and undocumented individuals) might elucidate interesting comparisons not possible with this design. The first author's familiarity with the immigrants' world and the clinic protocol may have prevented her from assuming the role of a true outsider. However, despite these limitations, the findings offer insights that can inform efforts to improve health outcomes for immigrant patients. To the authors' knowledge, this is the first qualitative study to explore the experiences of undocumented, Latina immigrants with chronic illness and to focus on the specific barriers to access and use of healthcare services created by their lack of legal documentation and healthcare coverage.

Implications for Practice

Caring must be carried out with a sense of the true worth of the patient, and must heed Taylor's (1994) recommendation that "the stance of caring needs to be motivated, at least from time to time, by the understanding of the other person as a lovable and worthy human being" (p.183). When we fail to recognize our patients as needing care, then our identity as caregivers is compromised (Malone, 1998).

Phronesis (or "prudence"), defined by Aristotle and distinguished from the other ethical virtues of *techne* (art or craft) or *episteme* (scientific knowledge), offers a paradigm of clinical rationality and intellectual virtue. The practice of phronesis leads to what Davis (1997) described as the prudential question of "what constitutes a *right* and *good* healing action for a particular patient" (p. 184). The importance of basing one's caring practices on *phronesis* is one of the implications for practice presented in this study.

Communication between patient and provider can be improved through the use of "cultural brokers." For example, the implementation of "health promotores" and community health workers to assist with chronic disease management, especially among Latino patients, has been shown to be effective in increasing patient empowerment and improving health outcomes in the clinical setting (Babamoto, Sey, Camilleri, Karlan, Catalasan, & Morisky, 2009; Castillo, et al., 2010; Norris, et al., 2005; Perez & Martinez, 2008; Thompson, Horton & Flores, 2007)

Implications for Policy Development

Taylor (1991) notes that the refusal of one's recognition can inflict damage on those denied in a broader social plane. He states "the projecting of an inferior or demeaning image on another can actually distort and oppress, to the extent that it is interiorized" (p. 50). Since providing healthcare for undocumented immigrants necessarily encompasses issues of recognition, the denial of recognition constitutes an oppressive act. In the larger political realm, recognition of undocumented immigrants can be accomplished by including them in the policy conversations that surround health and healthcare issues. But as long as they are unable to seek care except at poorly staffed, poorly resourced facilities, undocumented immigrants will continue to face barriers, since the limited resources also place caregivers in untenable positions and do not provide institutional support for caring practices to thrive.

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“Por La Necesidad”:

Situated Possibilities and the Healthcare Seeking Practices of Undocumented Mexican
Immigrant Women With Chronic Illness

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Abstract

Studies examining the effect of social determinants on the health status of Mexican immigrant women from their perspectives are scarce in the literature. This study addresses this gap by exploring stressors associated with women's undocumented status, and the barriers they face in caring for their chronic conditions. This interpretive phenomenological study examined the health care-seeking experiences of undocumented Mexican immigrant women with chronic illnesses. The women's situatedness in a world of circumscribed possibilities had greatly influenced their care-seeking practices. The women resorted to self-care practices including sharing medications or foregoing them altogether and relied on social networks to accommodate their lack of resources. Culturally-sensitive and compassionate care from healthcare staff and providers, as well as appropriate health policies that foster access to healthcare, may help minimize the stressors for such immigrants, enhance their resilience to health problems, and improve their health outcomes.

Keywords : uninsured immigrants, barriers to healthcare, stressors, social determinants, status syndrome, social networks

Introduction

Each year, thousands of immigrants journey across the Mexican border into the United States without legal authorization. Of the over 11 million undocumented Latino immigrants in the United States (U.S.) today, 35% are women (Pew Latino Center, 2010; U.S. Department of Commerce, 2006). Undocumented Mexican immigrant women tend to be impoverished, to live in unsafe housing, to work in low-paying jobs, and to experience discrimination and racism (Vega, Rodriguez, & Gruskin, 2009).

The role of social determinants upon an individual's health has been the subject of much debate among public health researchers and bioethicists, with many studies examining the effects of socioeconomic status on the burden of disease (Clark, Bond & Hecker, 2007; Juster, McEwen, & Lupien, 2010; Logan & Barksdale, 2008). In his social gradient framework, Marmot (2006) claimed that social position and socioeconomic status are responsible for health inequalities, a phenomenon he calls the *status syndrome*. People with low social statuses also have low social participation and lack control over their social conditions (Marmot). Sustained exposure to various social stressors, such as living in poverty, living and working in unsafe and unhealthy environments, and laboring at a menial job, compromises individual autonomy (Marmot). Having poor control over one's circumstances, and the failure to be integrated into the mainstream of society can place a physiological toll on the individual through the activation of the hypothalamic pituitary-adrenal axis, leading to chronic production of cortisol, which increase rates of obesity and other metabolic syndromes (Marmot, Shipley, Hemingway Head, & Brunner, 2008).

Mexican immigrant women are a particularly vulnerable population (Derose, 2000). Mexican women have a higher prevalence of CVD risk factors (e.g., high body mass index, high blood pressure, and low levels of physical activity) (Winkleby, Kraemer, Ahn, & Varady, 1998). Among MIW, diabetes is the fourth leading cause of death, and the major cause of morbidity among MIW who are 45 years or older (Aguirre-Molina & Molina). The rate of diabetes (10.9%) for MIW is more than twice that of White women (4.9%) (Ramos, et al). MIW who develop diabetes tend to be younger at the time of diagnosis, have poorer glycemic controls, demonstrate more insulin resistance, and experience more complications from the disease (Peralta, et al., 2006).

Previous studies describing the effect of stress on the health status of Mexican immigrant women have relied primarily on epidemiological findings, including survey data (Finch & Vega, 2003; Gallo, Jimenez, Shivpuri, Espinosa de los Monteros, & Mills, 2010; Kaestner, Pearson, Keene & Geronimus, 2009; Salgado & Snyder, 1987). Missing in the health literature are accounts of the immigrant women's experiences of stressors from personal and socioeconomic forces. Health care providers and policymakers need an adequate knowledge of the personal and social factors that may contribute significantly to the poor health outcomes of this patient population.

This study addresses these gaps in the literature by exploring the stressors associated with the undocumented status of Mexican immigrant women, and the barriers they face in caring for their chronic conditions while experiencing limited access to healthcare. This interpretive phenomenological study examined the lived experiences of undocumented Mexican immigrant women with chronic illnesses.

Stressors Experienced By Undocumented Mexican Immigrant Women

Mexican immigrant women who arrive in the U.S. by crossing the border without proper authorization experience many personal and socioeconomic stressors (The 2007/2008 Forum on Migration and Health). The pressing need to earn money is what drives many of these women to seek opportunities in the U.S., even if it means having to endure the anguish of leaving behind the familiarity of their homes and families, as well as encountering numerous fears of the unknown (McGuire & Georges, 2003; McGuire & Martin, 2007). Upon arrival in the U.S., many immigrant women suffer from culture shock, and what McGuire and Georges describe as “intense loneliness, a sense of initial disorientation and isolation, exacerbated by the language barrier and family separations, especially from children”(p.188). Fragmentation of the family structure is often the source of mental anguish in women who leave their children and other family members behind (McGuire & Martin). These women are often preoccupied with thoughts of achieving family reunification, even at the expense of entrusting their children to smugglers (McGuire & Martin).

Undocumented immigrants must also live under a persistent threat of apprehension by authorities and deportation (Berk & Schur, 2001). Many undocumented immigrants are forced to live in secrecy, resorting to a practice known as “passing” to keep from being discovered as people without authorization to be in the U.S. (Hall, Stevens & Meleis, 1994). They do this by assuming false identities, using green cards, social security cards, driver’s licenses or work histories that belong to others or are counterfeit (Schlosser, 2003). The fear of deportation and its consequences are elements

of an acculturation stressor called by Finch and Vega (2003) as “legal status stress.” An undocumented immigrant exhibiting this type of stressor is more likely to report her health as being fair or poor. This state of persistent hyperarousal adds to the cumulative effect of stress experienced by many undocumented individuals (Sullivan & Rehm, 2005).

Mexican women who are recent immigrants are also more likely to be impoverished than their U.S.-born counterparts (22 % versus 18%, respectively) (Pew Latino Center, 2010). In California, over one-fourth of Latino immigrant families live with annual incomes below the Federal Poverty Level (FPL), equivalent to a per annum income of \$22,350 for a family of four (Federal Register, 2011). This is true even when both parents work (Wallace, 2007). Women with incomes below the FPL are more likely to be uninsured and dependent on Medicaid as a source of healthcare coverage (Rodriguez & Carrasquillo, 2003). However, undocumented immigrants are ineligible for Medicaid, and usually must rely on the safety net systems that serve those with no other access to health care (Rodriguez & Carrasquillo). Immigrant Mexican women are also less likely than their U.S.-born counterpart, to be employed or, if they are employed are more likely, to work menial jobs that are usually without employer-based healthcare coverage. (Pew Latino Center). As is often the case, a great percentage of an immigrant’s earnings might be sent back to Mexico (in the form of remittances) in order to help support family members that were left behind (Organista, 2007; Massey & Parrado, 1994). Finally, having low incomes usually means that Mexican immigrant women must

reside with their families or often several other families in low-income housing, frequently in unsafe neighborhoods. (Marshall, Urrutia-Rojas, Mas, & Coggin, 2005).

Method

This interpretive phenomenological (IP) study was grounded in the philosophy of Heidegger (1927/1962), as interpreted by Dreyfus (1991), and as applied to nursing through the work of Benner et al. (Benner, 1994; Benner & Wrubel, 1989). The goal of research informed by IP is to understand the world of the participants from their vantage point, appreciating the cultural and social influences that have shaped their experiences of the world (Heidegger). The basic premise of IP is that human beings are self-interpreting, relational beings who are always already *thrown* into pre-existing world (Heidegger). The state in which we find ourselves in the world is what Heidegger called *thrownness* (or *situatedness*). The possibilities available in each person's life are a function of his or her being thrown into a particular culture, family or historical world (Benner, 1994). In the phenomenological tradition, the researcher interprets data to make explicit socially embedded meanings from the unarticulated, everyday lived experiences of the participants. IP is well-suited for analyzing the lived experiences of undocumented Mexican women living with a chronic illness because it facilitates analysis of everyday social discourse to reveal the concerns, meanings and taken-for-granted assumptions that shape their experiences (Heidegger).

Data Collection

This research was approved by the Institutional Review Board of the University of California, San Francisco. Study participants were recruited using word of mouth and snowballing methods. Data were collected using ethnographic methods, including interviews, participant observation and field notes.

Twenty-six undocumented Mexican immigrants gave verbal (because many were pre-literate) consents to be interviewed. In lieu of a signed informed consent, an IRB-approved study information sheet was used to further minimize identifiers. To maintain confidentiality, fictitious names were used in the following accounts. Study participants were paid \$15 for each hour of the interview.

We used an open-ended, semi-structured guide for the audio-taped interviews. Some of the topics discussed in the interviews were: (a) what the participants' lives were like before coming to the U.S., and what their lives were like at present, (b) what their illnesses were, and what they needed to do to manage them, (c) what they felt was the hardest thing about having to live with their chronic illness, (d) where they went for medical care, (e) how they paid for the treatment for their illness (including all necessary medications), and (f) how they perceived their treatment by healthcare providers and/or ancillary staff, in light of being uninsured. The interviews were conducted by the first author (who is partially fluent in Spanish) and also an interpreter who is both multilingual (i.e., someone who was completely fluent in both Spanish and English and also either in Triqui, Zapotec or Mixtec, if necessary) and multicultural to ensure mutual understanding, as well as provide additional translation when needed. The fieldwork took

place over the course of one year. The first author also had ample opportunities to work and observe some of the participants for three years prior to the start of the study (by providing them medical care as a volunteer nurse practitioner).

Setting and Participants

Twenty-one immigrant Mexican women (three Zapotecs, one Mayan, and 17 non-indigenous Mexicans) were recruited from a free clinic located in a small town in central California. A small sample of Triquis ($n = 1$) and Mixtecas ($n = 4$) were recruited from a farm-worker community situated about 50 miles from the coast. For a description of study participants, see Table 1. A total of 29 interviews were conducted. Three key informants were interviewed twice in order to seek more information and to confirm the meaning of narratives.

Criteria for inclusion were that a participant: (a) lacked legal documentation (i.e., the participant entered the U.S. illegally or overstayed their visa); (b) had a diagnosis of a chronic illness [(the CDCP definition of a chronic illness is one that is prolonged, lasting three months or more, continues indefinitely, is recurrent and generally cannot be prevented by vaccines or cured by medication (Center for Disease Control & Prevention [CDCP], 2000)]; (c) lacked full-scope health insurance (i.e., the participant must not have any private or public insurance; although she may have qualified for temporary state health insurance [e.g., for the treatment of tuberculosis, management of pregnancy, etc]); (d) was of Mexican origin (i.e., born and raised in any of the provinces of Mexico; and (e) was a female at least 18 years old.

The free clinic where the majority of participants were recruited serves the uninsured individuals of a local community. The clinic is open one evening a week for three hours, and is staffed primarily by a cadre of volunteers, who include lay people, nurses, physicians, nurse practitioners, physician assistants, nursing students and student interpreters. The clinic provides free medical visits, diabetic supplies and laboratory services. Triage and entrance tokens to the clinic are distributed before clinic hours by a Latina gatekeeper who has no formal medical training.

Data Analysis

Data collection and analysis occurred simultaneously, and were iterative in nature. Questions were added to the initial interview guide as participants expressed new themes during the course of data gathering. The taped interviews were transcribed verbatim, and subsequently translated into English by multilingual and multicultural translators. The transcribed and translated narratives were entered into a qualitative data management software (*Atlas ti*) to assist with data organization and coding of the text. Each narrative was read multiple times to gain a holistic understanding of the participants' experiences and to look for "incongruities, puzzlements, and unifying repeated concerns" (Benner, 1994, p.113). Interpretation of the narratives was done in hermeneutic phenomenological tradition, which involved three levels of analysis: exemplars, paradigm cases, and thematic analysis.

The first author extracted exemplars (smaller narratives or portions of narratives) from the text to illustrate each identified theme or pattern of meaning, and developed a series of paradigm cases (individual stories of a select group of participants whose lives

reflect the concerns, practices and circumstances experienced by the women, in general).

Paradigm cases allow an insider's look into the participants' lives, with the goal of hearing and understanding their voices. Thematic analysis consisted of identifying specific segments of the texts, coding and grouping them into recurrent themes.

Methodological Rigor

Triangulation, member checks, thick description, prolonged engagement and reflexivity were used to enhance validity (Creswell, 2007; Whittemore, Chase, & Mandle, 2001). As part of triangulation, multiple methods and data collection approaches were used to confirm the information gathered (Guba, 1981). Consultations with interpreters and several participants provided member-checking to ensure that the meaning ascribed to the narratives indeed captured the essence of the participants' experiences (Guba). From a Heideggerian stance, member checking means understanding the world of the participants from their vantage point, and being able to convey, respectfully their "taken-for-granted meanings, practices, habits, skills, and concerns" (Benner, 1994, p. xviii). The researcher has succeeded in making a valid interpretation, according to Dreyfus (1991), when she is able to put into words what the participant has always known, but did not have the words to say. Thick description gave detailed accounts of the phenomenon being studied, painting a vivid picture of events and persons within a societal context. Subsequently, various portions of the raw narrative data were discussed with an interpretive group that met biweekly and with a dissertation committee made up of qualitative and quantitative researchers, with extensive experience working among ethnic minority and immigrant populations. Prolonged engagement entails spending sufficient time in the field to allow the researcher to go beyond their preconceived understanding of the phenomenon of interest (Cohen & Crabtree, 2006). The time spent engaged in the phenomenon should adequately facilitate familiarity to the degree that the researcher is able to discern inconsistencies in the data. Practicing

reflexivity throughout each step of the data collection and analysis processes is important because the researcher is the instrument through which the phenomenon is revealed (Lincoln & Guba, 2003). Reflexivity allows the researcher to keep separate her own perceptions and biases from the meanings held by the participants about their own lives, illnesses, and experiences (Lincoln & Guba).

Findings

A person is *constituted* and shaped by her particular world through “the nonreflective taking up of the meanings, linguistic skills, cultural practices, and family traditions” (Leonard, 1994, p.47). Consequently, she is not a radically autonomous agent, i.e., one who has ownership and sole control of her life (Leonard). Rather, she is *thrown*, or *always already situated* in a world which delineates what options and possibilities are available to her (Heidegger, 1927/1962). The healthcare possibilities available to the Mexican immigrant women in this study were circumscribed by their thrownness into the particular world in which they had to live, including being undocumented women who have very limited social, cultural and economic capital. These limited possibilities defined the practices of the immigrant women participants such that they: (a) felt they were not free to choose where to seek their medical care, (b) did not receive the care they desired, (c) experienced multiple constraints in managing their illness, and (d) suffered debilitating effects of going under- or untreated in their medical conditions.

The women responded by making accommodations in their everyday lives in order to care for their chronic illnesses by foregoing needed medications due to expense, or obtaining medications in any way they could, not seeing physicians when it seemed

necessary to do so, opting for less expensive self-help techniques, and passing falsified results to gain access to resources.

“Por La Necesidad”

Understanding the *situatedness* of the immigrant women, as well as their extraordinary ability to survive, is critical to fully understanding the world in which they live, and the reason behind their healthcare seeking practices. *Por la necesidad*, literally translated into English as, *because of the need*, was a common refrain verbalized by the Mexican women interviewed in this study. *The need* most often expressed was the woman’s consideration of what is of a higher value that influenced her to make difficult decisions, usually out of a sense of desperation. The women persevered “through it all,” leaving behind all that was safe and familiar to them (e.g., their surroundings, culture, language, and most importantly, loved ones), because of the need—such as the need to pursue the “American dream,” or simply escape a life of abuse or deprivation in Mexico. For most of these women, their move to the U.S. has been permanent, having no prospect of ever going back to their home country because they lack legal “papers” and, therefore, would be likely to be deported if they were apprehended crossing the border. Also, in Mexico, there were no possibilities to have a livelihood sufficient to fulfill the hopes and dreams they have for themselves and their children. A woman’s past experiences shed some light on the nature of the “necessities” that often led her to feel that her only choice was to make undesirable sacrifices.

Rosa’s story illustrates the kind of life many of the women had that situated them to begin their lives in America:

At age thirteen, Rosa was abducted from her home in Oaxaca, Mexico by a man who would later abuse her, and who Rosa describes as “someone who has no respect for people...for a woman.” After forcing himself on her, Rosa conceived her first child. When the man (the term Rosa prefers to call him, instead of “husband,” which he was by common law) heard of her pregnancy, he ordered her to abort the baby, which Rosa did. Eight days after the abortion, he forced himself on her again, and again she conceived. At age 14, she gave birth to her first child. Things were calm in the home for about three months. Then, the man started drinking and causing a lot of grief for Rosa and her newborn. Later, she gave birth to several more children in rapid succession. Because the man provided neither food nor money to support the family, Rosa began to wash other people’s laundry to earn money. This only created anger and suspicion in his mind--he accused her of having another lover. He began to beat her even more than before.

Rosa continued to suffer this type of abuse from the man who would come to father all nine of her children:

...every time that he had me, it was by force, and if I didn’t let him it was by beatings. Sometimes he would cause me to bleed and I would tell him I didn’t want to anymore... “no well, he says, because you have lovers, you have people that’s why you do this.” Well, whether or not I let him it was always torn clothes, he would grab scissors and would cut it. Well, it was a very ugly thing that he did

Rosa was finally able to “get out of his power” when an obstetrician, after she nearly hemorrhaged to death during the birth of her ninth child, showed mercy to her by removing her uterus (despite her husband’s refusal to sign the consent form for the

hysterectomy). However, just when things appeared to be changing for the better for Rosa, she was hospitalized again. In Rosa's mind, it was during this hospital stay that she contracted tuberculosis (TB). Her TB symptoms did not become manifest, however, until two months after she was discharged from the hospital. At the same time, she had decided to cross the border illegally with her daughters to the United States. Rosa's border-crossing experience was fairly typical for these women. She and her daughters had to lay prone in the back of a flat-bed truck, all of them hidden beneath wooden planks and motorcycles. The *coyotes* (or human smugglers) instructed them to be quiet once they reached the U.S.-Mexico border, signaling to the women their arrival at the border by tuning the radio to a Mexican station. Rosa was not aware that she had active tuberculosis at the time, and had a strong urge to cough. However, she managed to overcome the urge due both to her extreme fear of being apprehended and her intense desire to get to the U.S. and work to support the seven children she left behind in Mexico. A month after arriving in the U.S., Rosa was again hospitalized, this time for her tuberculosis. Rosa's tuberculosis had badly scarred her kidneys, causing sudden, sharp pains that came over her intermittently, often rendering her unable to work. Her bouts with chronic, excruciating flank pain caused her to occasionally seek relief from the ED at a local hospital.

Living in a World of Situated Possibilities

According to Benner & Wrubel (1989), an individual does not have a "precognitive intentionality" whereby she is free to choose all her actions all of the time. Rather, her freedom is situated, allowing her to enter situations with her own "meanings,

habits and perspectives and that this history actually sets up the possibilities in the situation” (p. 54). The meanings, practices and concerns of the immigrant women in this study guided their practices seeking care for their chronic illnesses. Many of the women expressed their inability to choose where to go for medical care. Even though the care offered at the clinic where most of the women went was limited in scope, they “chose” to go there because they were not charged for their visits or for laboratory services. Despite having received free care, however, many of the women expressed frustration with their limited choices in medical care. They also shared a general dissatisfaction with the services they received. One woman said: “Do you think if we had money that we’d be getting services from that clinic? Because we don’t have insurance, and sometimes we don’t have money because--the consultation, the medications--it all adds up, and it’s expensive. Sometimes we have the money one month, but we don’t have it the next month.” This woman verbalized the commonly held frustration of what it must be like to always have to live on the edge of uncertainty, having little control over the possibilities in life.

Before deciding to seek care at the free clinic, some of the women sought care at a local community health center where they were charged sliding-scale fees based on income. However, even the reduced cost for a physician visit at one of these centers--usually the equivalent of at least a day’s wage for them--was still unaffordable for most women. For this reason, despite their dissatisfaction with the care they received, study participants persevered in going to the free clinic. As one woman said: “because one goes there for *the need*; because one doesn’t have to pay somewhere else.” The need for free

care made this woman willing to tolerate the many down sides of going to the free clinic, e.g., standing in the cold or rain when outside, then waiting long hours to be seen by a provider when finally inside, then perhaps only to be turned away because the volunteer physician fails to show up.

Many of the immigrant women went to the clinic hoping to receive specialized care for specific medical problems. Lydia, a 37 year old participant, went to the free clinic one evening hoping to get a dermatology consult for a worrisome mass in her left thigh. She expressed her concern about the mass: “I tell you if it continues to get bigger and then what happens is that it hurts and I don’t know what it is. If what I have there can damage my leg or I don’t know.” She described how the physician who was volunteering that evening examined the mass: “he moved it from one side to another, to one side to the other and ever since then the pain has become much stronger and it’s growing more...the doctor told me they were going to send me to a dermatologist.” The physician had poked and prodded the mass, seemingly regarding it as if it was an object that was distinct and unattached from the patient. To Lydia, however, the mass represented the embodiment of all her concerns, fearing that the mass presaged a diagnosis of the worst kind. After being manipulated a few times, the mass on her thigh was now more painful than ever - the pain was a constant reminder to Lydia of her need of care and the limited possibilities in her life to obtain that care. Though the physician promised to give Lydia a specialty consult for her mass, he failed to fully *apprehend* the meaning of Lydia’s concern over the true nature of her growing mass. For reasons that were not explained to her, Lydia was later

denied the dermatology referral, while another man and his daughter received the very consult she was hoping to get:

a man who got there after me was seen first, and when he came out he sat next to me to wait for his daughter's prescription, and he said that they were sending his daughter to a dermatologist. And I told him, 'oh you are lucky to go right in' and he told me 'the luck is that I became friends with that man (pointing to one of the clinic staff).

Lydia expressed extreme disappointment over her inability to receive the consult she wanted and to share her grievance with someone with more authority about the unfair arbitrariness in the way medical consults were given at the free clinic. Lydia went on to say: "For me there wasn't a dermatologist to see me...but for those that became friends with the man, there is a dermatologist for their daughter." Lydia's words communicated a sense of helplessness (and disappointment), revealing the reality that women like her do not have extensive social capital, having very limited possibilities in how to deal with their chronic illness. The possibilities of getting good care in Mexico at no charge, however, had been almost nil: "in Mexico, if you don't have money there, they don't, don't do nothing, not even check you or anything. Over there, your, money first and then they check you. And, even with money, they do not give great service. Here, in the United States, I expect different."

Most of the participants had come to the United States "in search of better horizons." Lydia was no exception. She said that when she had first arrived in America, she possessed an idea that was typical for the women interviewed, namely she had the

“*illusion* that one comes with to change our lives.” She confessed to “not having all one would want, but it is a little better than back in the home country.” Situations like this one reminded Lydia that she had not yet achieved her “dream.” Her aspirations to broaden her possibilities in the U.S. may have been just a false hope, anyway, because, after years of living in the U.S. the dreams of a “better life” sometimes felt more remote than ever.

Because of their lack of health care coverage and limited financial resources, the astronomical costs of managing their illness presented enormous challenges to many participants. Celia, a 46 year old participant who self-identified as being of Mayan descent, came to the U.S. to escape a life of poverty and an alcoholic husband, who she said “gave me a bad life, and ruined me a lot.” With much regret, Celia left her three daughters in Mexico, escaping to the U.S. in order to find work to provide for them: “I had to come here or we die of hunger...there we did not have the ability to succeed and get ahead.” She was diagnosed with diabetes when she was in Mexico at the age of 23.

In the following excerpt, Celia emphasized the hardship she has had to bear the expenses associated with her diabetes care:

how am I going to do it? How am I going to see a doctor? The consultation is about \$100 and the medication is separate. Then, they tell you, ‘buy the machine, buy the strips, and buy everything.’ Well, for me it has been very difficult, because I say that sometimes I only work four times a week or two times a week. It is very, very, very difficult for me, buying medications, buying syringes, very difficult for me.

She expressed extreme frustration (reflected in her multiple repetitions of the word “very”) over the monumental task of controlling her diabetes in light of her financial limitations:

I never checked my sugar...because it costs too much. Sometimes the doctor tells me this medicine you have to take and when the medicine ran out I had to go see him again, and sometimes he would say, your diabetes is very uncontrolled, but I could not. I cannot do what you said to do...the food, the medicines I cannot do it all. I work and I do not have time to check my sugars at work.

Daily self-management of one’s diabetes can be an onerous task, even for someone who has good healthcare coverage. For those who are uninsured and have limited means available to them to cover healthcare costs, the demands of properly caring for one’s diabetes can, at times, seem impossible and overwhelming.

Celia also had several physical ailments besides her diabetes. She shared a story about her injured finger and the fact that she had been unable to afford a consultation with an orthopedic surgeon. She was unclear about how she injured her finger, but she had been bearing the disabling effects of her condition, keeping the finger from getting in the way of her workaday activities:

This finger, I cannot move it, I don’t know why. I grab something hot and I work cleaning all day, and every night, I have to help it like that or to bandage it up before going to sleep. I bandage my finger so that it doesn’t stick out like that because without the bandage it will hurt more. I already went to a *sobador* (a

masseuse), and they couldn't fix it. They said it was a tendon and can't get fixed, and to go to an ortho...; how do you say it? An orthopedist is going to cost me a lot of money, the truth is I just sleep with my bandage, it's been awhile since the finger has been like that, the bone cracks now every time I bandage it.

After years of having tried to find a treatment that worked, she seemed to have given up on any possibility of ever getting it repaired so that it functioned normally again. Because of the enormous expense, surgery or even a consult with an orthopedic surgeon was out of the question for Celia. When she was interviewed, Celia was just coping with the pain, the constant bone-cracking, and the peculiar way her finger would "stick out" beyond her ability to control it. Celia showed me her finger, waving it around like a detached appendage. She had found that the only way to keep her finger from interfering with her daily routine was to bind it (as part of her nightly ritual) and to subdue it.

Celia had already made several attempts to apply for Medicaid, being denied each time for not meeting the eligibility criteria:

Many times I went to apply and could not, they told me that for diabetics no, I had to be an old person with advanced age and be disabled or that the doctor said you cannot work or maybe have small children. They never gave it to me, not even an emergency MediCal, they never gave it to me, I attempted again recently but they denied me again, I have to go on like this... Well if one has good papers, one has more advantages, but well, no, I am undocumented.

“I have to go on like this”, she said. By “this,” she could have meant that she had to continue struggling with an unforgiving disease like diabetes, and a disabled finger (among other things), without receiving any help from the healthcare safety net system because she had no “papers.” It was common knowledge among the women participants that fake identifications and fake social security numbers could be easily purchased on the black market, but “good” papers were hard to come by. Authentic documents provided many “advantages,” including an entrance into the “system” where the resources could be found. Having a legal status places women like Celia on the same footing as those who were recognized as being legitimate, and were eligible to receive the “advantages,” one of which was health benefits. Here she seemed to be implying that as an undocumented woman, or one who did not have “good” papers, she was destined to always be living on the periphery of society, as an outsider looking in.

Accommodating To Having Limited Possibilities

The immigrant women employed a variety of practices to accommodate for their lack of resources to adequately care for their chronic illness. Foregoing medications or obtaining them in any way possible, for example, was a common practice. At some point in time, all the Mexican women in the study had gone without their medications because of the expense. One participant said: “We work to be able to eat, survive, and sometimes we can’t make ends meet. I have run out of medication, and I have not been able to get more.” The participants struggled to obtain money to pay for multiple prescription medications. Participants also commonly shared medications with others in order to afford the costs associated with managing their chronic illnesses. This was well

illustrated by Teresa, who had diabetes, received pills from her father who had Medicaid, and on occasion she would obtain some from a friend: “when I was detected with it (diabetes) there, from that point on, he (her father) gave me medicine, my friend also would give me pills.” Another participant developed a system of stretching her medications: “When I exercise a lot...my sugars are good....better yet I don’t need to take my medications. That’s why they last me so long. Also, when my sugars are low I don’t take them...because if my sugars go down more I would be hospitalized. I cannot afford that.” Their absence from work because of a hospital admission would jeopardize their employment. The women were acutely aware that they are easily replaceable.

“Fear of the numbers.” Some of the volunteer lay staff at the free clinic required patients with diabetes to show home-monitored blood glucose values as proof that they were trying to control their diabetes, even before being allowed to enter. It was not uncommon for the staff to withhold care from patients who did not meet these entrance requirements. When entrance was denied for this reason, the women said they had been blamed for being indolent, and had been shamed in front of other patients when they came with high blood glucose values. Leticia expressed her anxiety over the expectations by the clinic staff: “Sometimes one goes with the ‘fear of the numbers,’ the woman (the clinic gatekeeper) is strict, she told me, ‘if you do not lower your diabetes, if I see it is high, I will not accept you.’” Leticia recalled observing a particular woman who attempted to gain entrance to the clinic by altering her blood glucose (BG) results:

I was sitting next to a lady, and I asked her, ‘why are you doing that?’ She is inventing numbers, I asked her why are you lying; Why do they fake the

numbers? She told me, 'she will not give you an appointment if you don't bring your machine, pill bottle, and all the necessary items, she will not let you see the doctor, she will send you home.'

Many of the women admitted to having altered their results because they were afraid of being made to feel culpable for inadequately controlling their diabetes. Here the breakdown in the women's physical health was regarded by the gatekeeper as a character flaw, and their lack of health insurance was attributed to moral failure or weakness. Maintaining good health was communicated as strictly the patient's responsibility. The practice of trying to pass falsified blood glucose data for authentic appeared to be consistent with other behaviors practiced by these women in their quests to live successfully as undocumented individuals. As mentioned earlier, the women were aware of the practice of purchasing counterfeit social security numbers, and some may have done that to pass as documented persons. The immigrant women may have felt the need to practice the same type of *secrecy by passing* (Hall et al., 1994) fabricated BG values for legitimate ones to gain entrance into the clinic where the needed resources are located.

Eusebia, a 57 year old participant, suffered from severe retinopathy from uncontrolled type 2 diabetes. She had been in the U.S. for almost 30 years, and lived with her common-law husband in a two-bedroom apartment they shared with another couple. Eusebia had been unable to get a job because of her visual impairment. She felt guilty about being totally dependent on her partner of eight years. At the time of the interview, she was receiving care at one of the federally-qualified health clinics in a nearby town,

and was paying out-of-pocket for her clinic visits and medications. When Eusebia was first diagnosed, her physician wanted her to come to the clinic every month to closely monitor her diabetes until it was better controlled. Because she could no longer afford the cost of her monthly visits, Eusebia asked her physician to lengthen the intervals between her appointments. Her physician, however, was reluctant to do so because Eusebia's blood pressure was elevated. She told me her physician said: "I have to control your high blood pressure. I wouldn't want you to have a stroke." Upon hearing this, she said: "Oh, doctora, God-willing, it will not happen, give me a little break." Eusebia confided in me (the first author) that she was too embarrassed to tell her medical provider the truth--that she did not have enough money to pay for the multiple follow-up visits she was requiring. She would often ask for an extension between appointments from the clinic receptionist. Eusebia said she was "happy" with her current situation because her next physician's appointment was not for three more months. Eusebia shared her method of affording the expense of the medical visits and medications for her diabetes:

I have already started saving up, little by little, to be able to pay the \$45. I think this time she will ask for labs also. That's when I feel it's difficult, so when I run out of a medication, I say I'll go without this medicine, then I say, 'Oh, God, I don't have the money to pay for that one, too'. This is when I start to lose control.

Because many of her medical expenses were converging on her all at once, Eusebia felt that she was losing control of her circumstances. Feeling "happy" at having staved off the expense of a more-frequent medical visit, she moved in the next breath to fretting about

the possible consequences of not taking her blood pressure medications. She had already gone a month without taking one of her blood pressure medications, and she knew that two of her other medications were going to need refills soon. She said she could not afford to pay for all three medications at once, as she barely had enough money saved up to pay for her next clinic visit. She feared that she might suffer the sequelae (as her physician had warned her) of having uncontrolled blood pressure, a “thrombosis” or a “hemorrhage.” In Eusebia’s circumstances, a paralysis resulting from a stroke would be worse than death (becoming paralyzed to Eusebia would only make her more of a burden on her partner, further increasing her dependence on him, and severely curtailing her future possibilities). Yet she had no way to pay for the treatment that could prevent it, so she bargained with herself by taking only some of the medicine.

The Value of Work

Taylor (1985) asserts that human identity and human agency are fundamentally characterized by the strong evaluative discriminations we make of the worth of our different desires. The Mexican immigrant women we interviewed made *strong evaluations* of their ability to work and earn money to support themselves and their families here and in Mexico. Working allowed these women to expand existing possibilities or create new ones in their lives, and thereby regain the ability to fulfill their constituted purpose. For every woman interviewed, her illness had disrupted her life in many significant ways, preventing her from functioning smoothly on a daily basis. Her illness had also severely damaged her ability to provide for her family:

Well, we come to this country to work, and now, I have no job. It's better here because there is a little bit of work so one can support oneself to live...and there (in Mexico) there is no work and it is very expensive to live there...so my daughters and I came here.

Many women became anxious about being unemployed. One expressed her desperation over her seemingly hopeless situation:

Well...there is no work. One cannot work and cannot support oneself very well....Well, when I become anxious, yes. But then one tries to control oneself and sometimes we just have to keep making an effort and trying until things get better. But the truth is...I get anxious, I get anxious.

Rosa, a participant mentioned earlier, had been told by an emergency room physician that she needed laser treatment on her compromised kidney. An intelligent decision for anyone in her physical state would have been to attend to her other kidney before it, too, became compromised, leaving her to face even graver consequences. However, the pressure to find a livelihood occupied her thoughts. She said, "Right now, what I need is to look for work and work even if they tell me I shouldn't. They would have to operate, the doctor said, and I said 'yes,' but now I tried to look for how to go about this, but I am not given the chance." Unlike a radically free agent who can choose the medical services that would lead to having the greatest potential of preserving her kidney, Rosa's choices were circumscribed by her present circumstances (her joblessness and her dependence on her daughters).

To Rosa, and most women interviewed, being sick had come to mean much more than just the absence of good health and well-being--being ill was also tantamount to being unable to work, and all that this entailed. Work was *constitutive* of who Rosa was; in other words, work, to a great extent, was what gave meaning to Rosa's life. Not being able to work nullified her constitutive purpose and was the very reason she came to America in the first place, namely to earn money. Like most women in the study, Rosa had left her most precious possessions behind in Mexico—in her case, her seven youngest children. However, working had opened new possibilities for Rosa, creating options for her life—and that of her children-- that she would not have had otherwise:

Well, it was good I worked because I got my son out of jail...I sent money for the others that are in Mexico so they have food to eat, so my children can eat...I send \$100 that's why, I tell you, I've killed myself working...I don't have five cents to my name.

Hard work was the only thing that saved Rosa and her children early on, when her husband either could not, or would not, provide for them. Working had helped her gain emancipation from living under the tyranny of her common-law husband. Being able to earn even a pittance has broadened her options in life, and freed her from total dependence on others. She relied on her daughters for food and shelter. Though she says she is thankful for their provisions, she feels frustrated with her present circumstances: “What is really frustrating me is this...I would like to go out myself to work...I would like to send my children money because I don't like being like this...I feel worse being at home and not working.” Though Rosa said she had always kept her family in the

preeminent position, her overriding concern was to be able to work: “I only like my work, and I’m dedicated to my work, and what’s more, nothing else matters... what I care about is my work.”

Discussion

As illustrated in their narratives, the Mexican immigrant women participants found themselves already situated in a world that circumscribed the possibilities available to them. Their lack of documentation and lack of healthcare resources limited their healthcare possibilities and affected their healthcare seeking practices.

The women were constrained (as well as motivated) by “the need,” which can be considered as the embodiment of all that mattered to them, what Taylor (1989) calls strong evaluations. A strong evaluation, according to Taylor, involves a discrimination a person makes of goods, qualitatively, as being “right or wrong, better or worse, higher or lower, which are not rendered valid by our own desire, inclinations, or choices, but rather stand independent of these and offer standards by which they can be judged” (p. 4). The qualitative discriminations a women made about which possibilities she pursued was based on her *interpretations*, or her understandings of what mattered most. Taylor points out that these interpretations compel individuals from time to time to accomplish a certain end. Ultimately, Taylor says, “to be human is to be already engaged in living an answer to the question, an interpretation of oneself and one’s aspirations” (p. 75). In a non-reflective way, these immigrant women pursued practices based on their situated healthcare possibilities because of “the need.”

This study supports previous findings in the literature that suggested that uninsured individuals often attempt to overcome the barriers they encounter when receiving sub-optimal health care from U.S. safety net systems (Becker, 2004). Becker found that uninsured individuals frequently accommodated for their lack of health care resources in much the same way as the participants in this study did, namely by: (a) delaying care because of cost, (b) either going without prescribed medications, or being under-medicated, and/or (c) reporting negative experiences while seeking care in the safety net system due to their lack of health insurance. However, even though the immigrant women's reactions to the barriers they encountered to care in this study were similar to those found in Becker's study, the motivation behind the women's actions may be better understood as being constrained by "the need" to ensure their own welfare and that of their families.

The high value these women placed on work may account for the differences in the findings from those from previous research (Becker, 2004; Becker & Newsom, 2003). The present study suggests that uninsured Mexican immigrants are not deterred from seeking medical care by their dissatisfaction with the safety net system. Rather, the women tolerated such things as: (a) being mistreated and discriminated against by healthcare staff, (b) having to endure long periods of waiting, and (c) receiving suboptimal medical care, all *por la necesidad*, or because of the need.

The sense of having no to little control over the quantity and quality of medical care a woman received evoked several responses, mainly feelings of shame, frustration and/or anxiety. Whereas the cause of a woman's feeling shame had been rooted in the

discrimination she perceived that was a result of her being uninsured, the frustration and anxiety were the result of being unable to obtain the care and health resources she expected. Most of those women who had to live with debilitating symptoms, and had been unable to acquire the care they felt they needed, expressed feeling such as being highly anxious, being unable to sleep, and having a sense that they were losing control of their lives, altogether. These “feelings, emotions and aspirations,” according to Taylor (1989), are what anchor our strong evaluations and motivate us (p. 67).

Studies such as this one can inform policy and praxis by revealing the practical consequences of barriers to access. Quantitative surveys cannot fully measure what is truly at stake for these women in the world in which they live, and have a tendency to interpret the women’s actions in reductionistic and objectivist terms (Taylor, 1989). Therefore, they must be “complemented by narratives, ethnographies, and social histories that speak to the complex, even contradictory, human side of suffering” (Kleinman, Das, & Lock, 1997, p. 15).

The results of this study confirm the notion expressed by Marmot (2006) and Marmot et al. (2008), that individuals of low socioeconomic status and social position, such as the undocumented Mexican women without healthcare coverage in this study, suffer from inordinate amounts of stress because of the lack of control over their circumstances. These stressors may help explain the deterioration in health and increased mortality rates commonly seen among Mexican immigrants after several years of living in the U.S. (Kaestner et al, 2009; Vega, 2009). Marmot proposed that low social status leads to low social participation that, in turn, can have a powerful influence on the risk of

developing disease. The Mexican women in this study, however, potentially challenging Marmot's theory, built social networks as a form of resilience (Hall, et al., 1994) in helping them surmount the many obstacles they encountered to obtaining care. The results of this study also concur with findings from previous research (Derose, 2000; Menjivar, 2002) that social networks are investments in social capital which can bear fruit in the form of resources to help in the care of health problems (in this case, helping the women manage their chronic illnesses). The participants often sought out family and friends for such things as: (a) helping them to obtain finances to pay for prescription medications they lacked, (b) sharing medications with others who also had limited means, (c) to help them find more affordable treatments (e.g., prescription medications from Mexico), and (d) helping them find health care services for a specific medical complaint (e.g., dermatology consult).

Moreover, these research findings extend the current knowledge base by revealing that the strong value placed on survival, even against significant odds, characterizes the lives of many Mexican immigrant women. The value attributed to *work* by the immigrant women interviewed was also a motivating factor in their desire to maintain good health, and is at odds with views that undocumented immigrants come to this country in order to seek social services. Rather, the women's decisions to relocate had often been based on the desperate situations in which they found themselves in Mexico, coupled with a keen desire to better their families through working. The narratives of the women interviewed captured the emotional anguish they felt in not being able to access care for the proper diagnosis and treatment of their debilitating symptoms. More importantly, this study

presents a different way of *evaluating* the healthcare seeking practices of these chronically ill immigrant women. The positivistic way of doing research has been criticized by some nurse researchers because “the meaning of the person’s or family’s life world, their lived experience, their situatedness, their concerns, and what matters to them are left out of the picture” (Plager, 1994, p. 67). Benner (1994) calls this disengaged manner of reasoning of positivism “a systematic blindness to embodied, lived experience in learning, health, illness and any human transformation” (p. xiii). A better way of seeing the immigrant women would be as self-interpreting beings, already situated in a world of circumscribed possibilities.

Strengths and Limitations

The findings presented here should be considered in the context of the limitations inherent in the study design. For example, the study results may have been limited by the use of a small sample of undocumented immigrants who were all Mexicans and reside in the same small town. The first author’s familiarity with the participants’ world and the clinic protocol may have prevented her from assuming the stance of a true outsider. Recruiting a more heterogeneous, immigrant sample (e.g., including both documented and undocumented individuals) might provide a more textured view of the world of the women. However, despite these limitations, the findings offer insights that could inform healthcare practitioners and policymakers because of both its novelty and insight. To the authors’ knowledge, this is the first qualitative study to explore the care-seeking experiences of Mexican women with chronic illness, and to focus on specific barriers to

access and utilization of care created by their lack of legal documentation and healthcare coverage.

Although it was not the intent of the researchers to make the findings of this phenomenological study generalizable to all undocumented Mexican immigrant women with chronic illnesses. The themes from the narratives revealed culturally-embedded concerns and practices, and the particular ways of being in the world of these women living with a chronic illness. Without having the necessary resources their horizons were foreshortened by being unable to sustain the work that was constitutive of their very identities.

Implications for Practice and Policy Development

Based on Marmot's framework of social gradients in health, policies that guarantee health care to uninsured Mexican immigrants may not necessarily rid this population of health inequalities (Vega et al., 2009). Even if given free resources for their health care, many undocumented Mexican women will continue to reside in caustic environments, as well as be educationally and financially disadvantaged. Therefore, policies regarding undocumented immigrants should include improving social determinants of health, such as their living conditions, employment and education. For example, funding and creating more organizations that provide legal services (like the *California Rural Legal Assistance*) are critical in order to protect undocumented immigrants from being victimized by slum landlords and greedy employers. Also, fostering group solidarity and empowerment among immigrant populations is one significant way to build resilience in helping them combat socio-political and

environmental stressors. Supporting grass roots organizations, like, *Mujeres Luchadoras Progresistas*, initially a project created to generate income for migrant women, has grown in scope to provide “farm worker women with an opportunity to foster pride and mutual solidarity and to learn new skills in public speaking, leadership, accounting, and public education” (Stephen, p. 233).

The qualitative data from this study also suggest several ways that clinicians can provide more culturally-appropriate and compassionate care to this vulnerable population, thereby improving an immigrant’s abilities to exercise agency in choosing the health options she values most. For example, healthcare providers should be careful not to misconstrue certain patient practices, like foregoing medications and physician visits, as being willful non-adherence. Resources necessary to manage their chronic illnesses are often unavailable to many indigent, uninsured immigrants, many of who are persistently bound by financial constraints. Many providers maintain a typical market view of patients as consumers when working with uninsured immigrants, failing to realize that these clients often do not have the ability to choose from a menu of healthcare options (Malone, 1998). A clinician will be more effective in treating this population if s/he is aware of the effects of social determinants on their ability to adhere to clinical recommendations.

The Patient Protection and Affordable Care Act prohibit expanding the safety net systems to include uninsured, undocumented immigrants (Martin & Burke, 2010). EDs are often the last source of health services for the indigent. However, access to EDs for uninsured and indigent immigrant populations is threatened by the proposed curtailment

of the disproportionate share hospital funding source as part of the proposed health care reform (Martin & Burke). Providing better healthcare for immigrant populations such as the women in this study entails reducing the limitations brought by a restrictive healthcare system and changing current policies and programs to include the undocumented immigrant without healthcare coverage.

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Synthesis of Findings

This final section of the dissertation contains an analysis and integration of the thematic findings discussed in the three articles. The first article is an integrative review of selected literature that is pertinent to understanding the factors (e.g., personal, socioeconomic, linguistic and political) that may be contributing to the existing health inequalities among undocumented, Latina immigrants. Both quantitative and qualitative studies focusing on demographic characteristics and utilization of healthcare services among undocumented Latinas were discussed. The literature discussed in this review contains primarily surveys with large aggregate data sets. The literature suggested that other contextual factors might be at play in influencing the barriers to healthcare services among undocumented Latina immigrants. The literature review showed a paucity of qualitative studies conducted among this vulnerable group highlighting the importance of this research study.

The second article revealed that the health care seeking experiences of the immigrants in the study were often characterized by a lack of recognition of their human plight, and the devaluation of their personhood. Failure to recognize the healthcare needs of the women participants, on the part of both healthcare staff and medical providers, was perceived by these women as having been an obstacle to gaining the care they felt they needed. Objectification and disengagement were the outcomes when a reciprocal relationship of trust and respect between the women and the medical providers were lacking. The medical providers who resorted to objectifying their patients reduced them to a mere collection of signs and symptoms, rather than as human beings in need of

genuine care (Benner, 1994). The study also showed that there were instances when the women were treated as having equal value to their providers considered their medical complaints as being legitimate and worthy of care.

The third article articulated that certain constraints perceived by these women resulted from personal factors, most noticeably an internal *need* to survive felt by each woman. The Mexican immigrant women in this study found themselves already situated in a world that circumscribed the healthcare possibilities available to them. The possibilities the women pursued were based on their evaluations and interpretations of what is significant. Another personal factor that greatly influenced the women's care-seeking practices was their low socioeconomic status and the value given to work. The immigrant women's self-care practices such as sharing medications, or foregoing them, altogether, and reliance upon social networks were ways they attempted to accommodate for her lack of resources.

The purpose of this dissertation was to fill the information gap in the existing research literature about the healthcare seeking practices of a direly under-studied population-undocumented Mexican immigrant women coping with a chronic illness, but without the necessary healthcare resources. The review of the literature suggests that the barriers to accessing health care may extend beyond the lack of health insurance. Studies cited in the integrative review noted that an immigrant's perception of discrimination and marginalization by those within the healthcare system could explain the reason behind the decrease use of urgent and emergency care among undocumented immigrants. (Derose, 2000; Garces, Scarinci, Harrison, 2006; Horwitz, Roberts & Warner, 2008; Lauderdale,

Wen, Jacobs, Kandula, 2006). The literature also showed that immigrants who are both undocumented and uninsured report higher rates of unmet medical needs and dissatisfaction with the care they receive as compared to their documented counterparts (Derose; Iniguez & Palinkas, 2009).

The study findings help illuminate the reason behind the oft-reported unmet medical needs and dissatisfaction with the care received by undocumented, uninsured immigrant women while accessing care in the healthcare safety net system. More specifically, these findings suggest that the contextual factors influencing the healthcare seeking practices of undocumented Latina immigrants may not necessarily be from their reluctance to seek care as a response to their being poorly treated and marginalized. Rather, the failure of healthcare providers to recognize and legitimize their medical problems was the reason for the women's inability to access the care they felt they needed. Many of the women were repeatedly turned away or denied care when they sought care for life-threatening symptoms because of their lack of medical insurance. The lack of recognition these undocumented immigrant women felt when seeking healthcare might well go beyond issues surrounding the barriers to healthcare they faced, to barriers to social identity. The fundamental need expressed by all these women was the desire to be recognized simply, and wholly, as being *human*. Other barriers experienced by the women can be attributed to their lack of language skills and cultural health capital, as well as their low socioeconomic status.

Conclusion

The findings from this study extend the current knowledge base by revealing the strong value placed by the immigrant women on “the need”- or that which matters most to them. It is the same “need” that motivated them to make difficult decisions in their lives (even against significant odds) in order to ensure their and their family’s survival. Also, the present study suggests that uninsured Mexican immigrants are not deterred from seeking medical care by their dissatisfaction with the safety net system. Rather, the women endured such things as: (a) mistreatment and discrimination by the healthcare staff, (b) having to endure long periods of waiting, and (c) receiving suboptimal medical care, all *por la necesidad*, or because of the need. The women expressed the emotional anguish they felt in not being able to access care for the proper diagnosis and treatment of their debilitating symptoms. The value attributed to *work* and the keen desire by the immigrant women to better their families through working was also a motivating factor in their attempts to maintaining good health.

This study fills a critical gap in the literature by: (a) evaluating the healthcare seeking practices of the chronically ill immigrant women from their vantage point (and including their voice in the matter), (b) examining the true nature behind their constraints and motivation in seeking care, (c) suggesting a different explanation to the root of the healthcare access problem for this vulnerable group of immigrants, i.e., the failure by healthcare staff and providers to recognize the immigrant women as human beings with legitimate medical needs.

Implications for Future Policy Development

Undocumented immigrants are excluded from participating in most of the benefits proposed by the Patient Protection and Affordable Care Act (Kaiser Family Foundation [KFF], 2009). Despite the expansion of many public programs proposed under this piece of health reform legislation, these immigrants will continue to be ineligible for Medicaid benefits. They will also be prohibited from purchasing affordable health insurance through proposed state-based health care exchanges; apparently, the assumption here being that all undocumented individuals do not pay taxes, therefore none should be allowed to receive government subsidies or tax credits. In fact, every year undocumented immigrants contribute about \$7 billion to Social Security, and \$1.5 billion to Medicare even though they do not stand to benefit from them (Ponce de Leon, 2010). Creating health care policies that allow immigrants who pay taxes to accrue premium credits and purchase coverage in the market exchanges can help ameliorate the disparities (between the undocumented and documented immigrants) that currently exist in healthcare coverage and utilization of services. For routine care for their chronic conditions, the Latina participants in this study relied primarily on free clinics, public health clinics and public hospitals, as well as community centers. This pattern of health service utilization among Latina immigrants was also noted by other investigators (Chavez, Hubbell, Mishra, & Valdez 1986; Derose, 2000). Because many of the women could not afford the cost of a clinic visit (even when fees were on a sliding scale based on a person's income), EDs were often the only source of care available to them.

The Emergency Medical Treatment and Labor Act requires hospitals to provide care, regardless of a person's insurance, ability to pay or citizenship status. However, starting in 2014,

funding for the federal Medicaid Disproportionate Share Hospital will be phased out as part of the reform law (Martin & Burke, 2010). Hospitals, medical practitioners and community centers will no longer be reimbursed (or will incur quarterly reductions) for uncompensated costs from providing care to undocumented immigrants (KFF, 2009). This can result in large financial losses for these stakeholders, creating a disincentive for them to continue serving this population (Martin & Burke). The ED is often the last bastion of medical care for many indigent, uninsured immigrants. Eliminating future compensation for ED services will only increase the inequalities experienced by undocumented immigrants, especially those with chronic illness. Modifying current policies to include the healthcare needs of this vulnerable population is imperative in reducing the existing health disparities among undocumented Latino immigrants without healthcare coverage.

The current state of affairs could be redressed simply by modifying the Medicaid waivers currently being allowed by the federal government (i.e., the federal government permits states to amend its programs through waivers that are otherwise not permitted under federal Medicaid law). For example, in California, under the new Section 1115 waiver, MediCal eligibility will be expanded to include approximately 851,000 currently uninsured children and adults by 2014 (Department of Health Care Services, 2011). Some of the goals of this waiver that have relevance to undocumented immigrants are to: (a) expand the capacity of safety net hospitals to provide a medical home and care coordination for newly eligible recipients, (b) expand access to primary care, and (c) improve chronic disease outcomes for at-risk populations. One of the ways to address the limited access to care currently experienced by undocumented immigrants with

chronic illness, particularly to those who pay taxes, would be to include them as part of the group of newly MediCal eligible participants under Section 1115.

Implications for Future Research

Future research on access barriers should explore the differences between the care-seeking experiences of indigenous and non-indigenous Latina immigrants with chronic illness. The sample of indigenous immigrants in this study was not sufficient to make significant comparisons in the healthcare practices between the two groups. Also, investigating gender differences in healthcare experiences among this population of immigrants would be instructive to clinicians and policymakers. Obtaining the perspective of the healthcare staff and clinicians, as they provide care to undocumented, uninsured Latino immigrants in various healthcare venues (e.g., the ED, a primary practice clinic, etc.), can shed a different light on the findings of this study. Lastly, allowing the participants to choose the issues that are significant to them by using community-based participatory research would also be helpful in defining the access problem from an immigrant's vantage point.

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APPENDIX A

DEMOGRAPHIC INFORMATION SHEET

*Initials or Pseudonym: _____

*Age: _____

Please circle:

Are you single, married, divorced or living with your partner?

Do you have any children? Are they here or in Mexico?

Do you have family living in the United States? Yes No

What do you consider yourself?

a. Mexican	___	c. Zapotec	___
b. Mixteco	___	c. Triqui	___
		d. Other:	___

*How long have you lived in the United States? _____

*Who do you live with (family, non-family) ? _____

*What do you do for a living? _____

*What languages do you speak or understand? _____

*What was the last grade of school you completed?

*What type of medical insurance do you have? _____

*If none, how long have you been without medical insurance? _____

*Where do you go for your medical care? _____

APPENDIX B

UNIVERSITY OF CALIFORNIA, SAN FRANCISCO

RESEARCH STUDY INFORMATION SHEET

Study Title: Care-seeking Experiences of Undocumented, Mexican Immigrants with Chronic Illness.

This is a research study about how Mexican immigrants who are not legal citizens of the U.S., have no health insurance and who have a chronic illness find out about health programs or policies, and what things influence the way they get medical care.

Juliet Chandler FNP, MS, a doctoral student in the School of Nursing at UCSF will explain this study to you.

Research studies include only people who choose to take part. Please take your time to make your decision about participating, and discuss your decision with your family or friends if you wish. If you have any questions, you may ask the researchers.

You are being asked to take part in this study because you are Mexican, who do not have insurance and have no documentation and have a diagnosis of a chronic illness.

Why is this study being done?

The purpose of this study is to describe how Latina immigrants who do not have medical insurance, who are not legal citizens of the U.S., and have a chronic illness find out about health services that can help them. Also, we want to know what additional health programs are needed for Latina immigrants. We do not know very much about this subject, and would like to learn more about it in order to provide better health services to this group of people.

How many people will take part in this study?

About twenty to thirty women and the staff of the (name of clinic) as well as key leaders of the indigenous groups will take part in this study.

What will happen if I take part in this research study?

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

- You will fill out a form asking you some information about your age, your occupation, etc.
- The researcher will interview you for about an hour in a place that is convenient for both you and the researcher. You will be asked questions to describe your experiences about how you get information about health services, and your experiences as an uninsured person who cannot read or write English or Spanish. You may be asked to participate in a second interview if more information is needed by the researcher.

- The researcher will make a sound recording of your conversation. After the interview, someone will type into a computer what you and the researcher discussed on the tape, and will remove any mention of names. The sound recording will then be destroyed.
- The researcher will informally observe you and the people you interact with at your home during the interview (if the interview is done there). The researcher might also want to observe you at one of your doctor's visits (the investigator will request your permission before accompanying you to your scheduled visit).

How long will I be in the study?

Participation in the study will take a total of about 1-2 hours for each interview. If a second interview is needed, it will be done one month after the first interview.

Can I stop being in the study?

Yes. You can decide to stop at any time. Just tell the study researcher right away if you wish to stop being in the study.

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

What side effects or risks can I expect from being in the study?

- You might feel uncomfortable answering some of the questions in the interview. You do not need to answer any of the questions that make you uncomfortable. You can also ask the researcher to stop the interview at any time.
- You might become afraid of being reported to authorities. Be assured that none of what you tell the researcher will be used against you. The information you share with the researcher will be kept confidential, and will not be shared with authorities unless doing so will endanger your own and other people's lives.
- For more information about risks, ask one of the researchers.

Are there benefits to taking part in the study?

There will be no direct benefit to you from participating in this study. However, the information that you provide may help health professionals better understand or learn more about how to help people without insurance get better health care services, especially those who cannot easily get information about them because they have limited English or Spanish.

What other choices do I have if I do not take part in this study?

You can choose not to participate in the study.

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. However, we cannot guarantee total privacy. Your personal information may be given out if required by law. For example, if the researcher suspects you have a contagious disease that can infect others and threaten public health. If information from the study is published or presented at scientific meetings, your name and other personal information will not be used.

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

- UCSF's Committee on Human Research
- UCSF's School of Nursing faculty and other researchers

What are the costs of taking part in this study?

You will not be charged for any of the study procedures.

Will I be paid for taking part in this study?

You will be given \$15 after each interview (a total of \$30 if you complete 2 interviews) in return for your time and effort in the study. You will be paid in cash immediately after each interview you participate in.

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

Taking part in this study is your choice. You may choose either to take part or not to take part in the study. 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 you in any way.

Who can answer my questions about the study?

You can talk to the researcher(s) about any questions or concerns you have about this study. Contact Juliet Chandler at (phone number).

If you have any questions, comments, or concerns about taking part in this study, first talk to the researcher (named above). If for any reason you do not wish to do this, or you still have concerns after doing so, you may contact the office of the **Committee on Human Research**, UCSF's Institutional Review Board (a group of people who review the research to protect your rights). You can reach the CHR office at **415-476-1814**, 8 am to 5 pm, Monday through Friday. Or you may have a family member or friend write to: Committee on Human Research, Box 0962, University of California, San Francisco (UCSF), San Francisco, CA 94143.

APPENDIX C: INTERVIEW GUIDE

Thank you for agreeing to participate in the study. You may remember that the reason I'm doing this study is to know more about how Mexican immigrants who do not have insurance and have a chronic medical problem get the care they need.

Before I start the interview, I would like to ask you permission to tape record our conversation. No one will hear the contents of this tape except me and the translator who came with me today. The translator will be helping me with the interview, but I can speak and understand Spanish as well.

If at any point during the interview you begin to feel uncomfortable, you can refuse to answer the questions or stop your participation in the study altogether.

1. Tell me about yourself (things that will help me understand who you are, and anything else about your life in the United States). What was your life like before you came to the U.S.?
2. How would you describe your health?
3. Do you have any health problems?
4. What do you call your medical problem/condition?
5. How does your health problem affect your everyday life? What is the hardest thing about managing your symptoms/chronic condition?
6. How important is your health to you?
7. How do you take care of yourself? What do you do when you get sick?
8. How did you learn to do _____ to care for yourself?
9. How do you make decisions about your health? Do you ask anyone for advice about your health? Have you ever used alternative therapies?
10. Tell me what it's like not to have health insurance.
11. Tell me some experiences you've had trying to get medical care.
12. What do you do when medical help is not available when you need it?
13. How has not having insurance affected caring for your health problem(s)?

14. Have you ever been treated poorly when seeking care for your medical condition? Can you tell me the story about what happened?

Probes: What did you do?

What happened then?

15. How did you find out about the free clinic? (*If participants were recruited from the free clinic, explained in the 'data collection' section.*)

Probe: When was your last clinic visit? How did it go?

16. Have you ever sought care in an emergency department? What was your experience like?

17. How satisfied are you with the health care you are getting/ you received?

18. Tell me about the other health services or programs you use.

Probe: How did you find out about these?

19. Any other experiences or stories you would like to share with me?

Table 1: Journal Articles from Review of the Literature

Author/Yr	Purpose	Sample	Method/Design	Results
Hubbell, F., et al. (1991)	To determine local access to medical care among Latinos.	N= 958 Documented (doc) & undocumented (undoc) resident adults of Orange County, CA who were considered poor or nearly poor based on the national poverty level	Telephone surveys conducted at two separate occasions 5 months apart Questionnaire consisted of closed- and open-ended questions about demographics, access to care & health status.	Undocumented Latinos were less likely than Latino citizens to have health insurance.
Chavez et al, (1997)	To examine the sociodemographic characteristics of Latinas living in Orange County California	Latina women > 18yo N=803 Latinas (160 were Undoc)	Telephone surveys of a cross-sectional sample	Undocumented Latinas were younger than documented Latinas; compared with US citizen Latinas & Anglo women- both undoc and doc Latinas worked in menial jobs (e.g., domestic services); do not have job-related medical insurance, lack regular source of care, use public health centers & ED rather than private physicians & under-utilize preventative services.
Berk, M., et al. (2000)	to examine reasons for coming to the U.S., use of healthcare services, and participation in government programs.	N =1171 From 4 major communities in Texas & California, of different ages, country of origin, and varying family income	Probability sampling and in-person interviewing	Undocumented immigrants obtain fewer ambulatory care visits, lower rates of hospital admission, except for childbirth were

				<p>rates were comparable with other Latinos.</p> <p>Frequency of physician visits were lower for the undocumented immigrants</p> <p>Undocumented immigrants seldom use most public programs (such as Medicaid) serving the adult population</p>
Derose (2000)	To explore the principal problem Latinas face in getting healthcare (HC); how their experiences with the HC system affect them & how they overcome obstacles to get care for themselves & their families	N= 9 Latinas	Case study approach Semi-structured interviews	Latinas faced challenges getting HC; they felt embarrassed, scolded, helpless, discouraged because of their inability to communicate with providers. They overcame these obstacles through building solidarity & social networking with other Latinas
Berk & Schur (2001)	To determine whether concerns about one's immigration status serves as a deterrent to accessing healthcare	N=973 Latino Undocumented adults from Texas & California	In-person interviews	39% expressed fear about receiving services; were less likely to obtain medical, dental & preventative services
Ku, L. & Matani, S.,	To explore the sociodemographic and health-related characteristics of	N= 109,992 uninstitutionalized persons under the age	Secondary data large national sample good over-all response	1. Being an undocumented was associated with a

(2001)	immigrant Latino women, including migration status, perceived health status, health problems, and access to care.	of 65 from low-income populations from 13 states.	from surveys	substantial and significant reduction in access to ambulatory & emergency care 2. Being Latino was associated with getting less care, in general. 3. Undocumented were less likely to see a private physician or be enrolled in health maintenance organizations.
Menjivar (2002)	To examine how immigrant women obtain treatment for themselves because of the inaccessibility to formal HC resources	N=26 Ladinan & Indigenous Guatemalan women	Participant observations & Semi-structured interviews	The women obtained treatment for their illness through intricate social networks- local & transnational- from over-the-counter to prescription drugs brought from Guatemala
Iniquez & Palinkas (2003)	To examine the association between barriers related to health services access & use among Latinas & use of alternative forms of health services (traditional practitioners & health services in Mexico)	N=250 low-income Mexican-American women attending a community clinic in San Diego, CA.	Convenience sampling of Latinas who were interviewed after their scheduled appointment with a HC provider	Only 48.4% of the women had preventative services; 34.4% reported having obtained an annual exam in the past year, & 66% reported visiting a doctor only when they were sick. Lack of any form of health insurance was associated with underutilization of HC services.
Marshall et al (2005)	To examine sociodemographic, migration, health status & access to healthcare characteristics	N= 197 Undocumented and documented adult Latino women,	Cross-sectional study based on secondary data (survey)	Healthcare coverage was extremely low among the undocumented women

		representative samples of women from Texas.		in the study. Undocumented women were younger, lower level of education, and poor ability to speak English.
Freeman & Lethbridge-Cejku (2006)	To assess differences in accessing healthcare of 5 different Latina subgroups	N= 9082 Latinas (Mexican, Puerto Rican, Cuban, Central-American & Other)	Used data from 2000-02 National Health Interview Survey	Mexican women had the highest rates of uninsurance, having no usual source of care and experiencing unmet HC needs
Goldman, Smith & Sood (2006)	To estimate the service use & cost of care for non-elderly adults by nativity & type of immigrant including the undocumented	N= 2620 adults in Los Angeles County, CA	Stratified, random sampling; survey	Foreign-born (especially the undocumented) use fewer medical services & contribute less to HC costs- the undocumented constituted 12% of the non-elderly adults but accounted for only 6% of HC spending
Urrutia-Rojas, et al (2006)	To assess the access to HC services, health status & sociodemographic characteristics of Mexican immigrants	N= 319 Mexican immigrant adults who self-identified as being born in a Spanish-speaking country and resided in N Texas	Secondary data analysis of a cross-sectional study	Undocumented immigrant women tend to be young, have low education & live in poverty compared to documented immigrant women; 71% undocumented adults did not speak English; 9% of undoc vs 40.7% of doc had health insurance; >50% of undoc immigrants reported their health as poor; None of the respondents used public programs that

				provide HC
Ortega et al (2007)	To compare access to healthcare, use of services, & healthcare experiences for Mexicans & other Latinos by citizenship & immigrant authorization status	N =1588 Undocumented Mexicans and other Latinos, US born, naturalized, and those with green cards	Secondary data analysis from phone survey of 2003 Calif Health Interview Survey	Undocumented immigrants: -were least likely to report their health as good or excellent- -were more likely not to have usual source of care. -had lowest mean # of physician visits -were more likely to have difficulty understanding their physician -were less likely to report having problem getting necessary health care -do not have higher ED use Immigration status is an important determinant of access to care
Cristancho et al (2008)	To explore rural Latinos perceived barriers to accessing & utilizing HC	N= 181 Latino adults from 3 communities in the Midwest, US	Community-based participatory approach using focus groups	The most common barriers to care were the lack of HC coverage, high cost of HC services, communication issues, with providers, lack of documentation, discrimination & transportation concerns
Nandi et al (2008)	To assess access to & use of health services among Mexican-	20 min interviews in English & Spanish using	N=431 Undocumented	Social & family networks play key role

	born undocumented immigrants living in New York City in 2004	structured questionnaires	Immigrant Adults >18 y.o. living in New York City	<p>in accessing care.</p> <p>Those experiencing discrimination were less likely to access health services.</p> <p>Those with more health need were more likely to use emergency room care, but not have access to regular healthcare provider.</p>
Fuentes-Afflick & Hessol (2009)	To assess the relationship between immigration status & use of health services among Latinas	N= 710 postpartum Latinas from a public hospital (50% undocumented; 25% documented)	<p>Part of a larger multistate study</p> <p>Participants were</p> <p>Recontacted after the initial study & interviewed</p>	Publicly insured women were less likely to use dental care, preventative services & more likely to use emergency care; Undocumented Latinas were less likely t(60%) to have dental visits than documented Latinas (40%)
Heyman, et al.(2009)	To extend the concept of “patchworking” into the active healthcare-seeking paths of undocumented migrants, the range of barriers they encounter , and the resilience factors Involved	<p>N= 84</p> <p>Uninsured, 52 females, 32 males, 52 of 84 were undocumented</p>	Semi-structured interviews	<p>Direct barriers:</p> <p>increased demands for documentation; constant awareness of deportability; immigration law enforcement posed obstacles to movement to healthcare locations;</p> <p>Positive access factors were: networks, community support</p> <p>Health effects were”</p> <p>-Limited checkups</p> <p>-Responds to acute symptoms</p> <p>-Breakdown in follow-</p>

				up, monitoring and chronic care.
Rodriguez et al (2009)	To determine the relationship between nativity/immigration status & self-reported quality of care; to assess the impact of a usual source of care on receipt of preventative care	N= 4013 Latino adults U.S. born and foreign-born Latinos- nationally representative sample with varying documentation status	Cross-sectional study- used telephone survey	Undocumented Latinos had the lowest HC coverage (37% undoc vs 77% US-born; $p < .01$); usual source of care (58% vs 79%, $p < .001$); highest percentage of receipt of no HC services among the undocumented
Vargas Bustamante et al (2010)	To identify differences in HC access & utilization of services of Mexican immigrants with varying documentation status	N= 2600 documented; N= 1038 undocumented Mexican immigrant adults	Cross-sectional study' secondary data analysis of the 2007 California Health Interview Survey	Undocumented immigrants from Mexico were less likely (27%) to have had a doctor visit & less likely (37%) to have a usual source of care than documented counterparts

Table 2: Socio-demographic Characteristics of Study Participants

Age Range

<28 years	1	(4%)
29-44 years	11	(42%)
45-59 years	13	(50%)
60-70 years	1	(4%)

Marital Status

Single	5	(19%)
Married	10	(39%)
Divorced	4	(15%)
Separated	1	(4%)
Living with partner	6	(23%)

Length of time in U.S.

<5 years	3	(12%)
6-10 years	7	(27%)
11-15 years	8	(31%)
16-20 years	4	(15%)
>20 years	4	(15%)

Race/Ethnicity

Non-indigenous	17	(65%)
Mixteca	4	(15%)
Zapoteca	3	(12%)
Triqui	1	(4%)
Mayan	1	(4%)

Employment

Housekeeper	7	(27%)
Housewife	5	(19%)
Unemployed	5	(19%)
Fieldworker	3	(12%)
Babysitter	3	(12%)
Business	1	(4%)
Fast food	1	(4%)
Seamstress	1	(4%)

Education (number of years)

None	3	(12%)
1-3 years	5	(19%)
4-6 years	12	(46%)
7-9 years	4	(15%)
Vocational	1	(4%)
Bachelors	1	(4%)

Medical Diagnosis

Diabetes	23	(88%)
Unknown mass	2	(8%)
Renal TB	1	(4%)

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Juliet Chandler
Author Signature

July 19, 2011
Date