Health Disparity and Structural Violence: How Fear Undermines Health Among Immigrants at Risk for Diabetes

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ABSTRACT

Diabetes is a national health problem, and the burden of the disease and its consequences particularly affect Hispanics. While social determinants of health models have improved our conceptualization of how certain contexts and environments influence an individual's ability to make healthy choices, a structural violence framework transcends traditional uni-dimensional analysis. Thus, a structural violence approach is capable of revealing dynamics of social practices that operate across multiple dimensions of people's lives in ways that may not immediately appear related to health. Working with a Hispanic immigrant community in Albuquerque, New Mexico, we demonstrate how structural forces simultaneously directly inhibit access to appropriate healthcare services and create fear among immigrants, acting to further undermine health and nurture disparity. Although fear is not normally directly associated with diabetes health outcomes, in the community where we conducted this study participant narratives discussed fear and health as interconnected.

Keywords: Structural Violence, Health Disparities, Diabetes, Immigrants

> *"There is a powerful, enervating anxiety created by the limits of our control over our small worlds and even over our inner selves. This is the existential fear that wakes us at 3 a.m. with night sweats and a dreaded inner voice that has us gnawing our lip, because of the threats to what matters most to us"*
> (Kleinman 2006b, p. 6)

> *"… it has long been clear that medical and public health interventions will fail if we are unable to understand the social determinants of disease"*
> (Farmer, Nizeye, Stulac, and Keshavjee 2006, p. 1686)

INTRODUCTION

Diabetes has become an epidemic problem in the U.S. (Boyle, Thompson, Gregg, Barker, and Williamson 2010; Centers for Disease Control and Prevention 2011). Approximately 8.3% of the population (or 25.8 million people) suffer from diabetes in the U.S., with the majority (nearly 95%) having type-2 diabetes (Centers for Disease Control and Prevention 2011). In addition, nearly one-fourth of the population has been diagnosed as pre-diabetic (Centers for Disease Control and Prevention 2008) and trends suggest that diabetes prevalence may increase to as many as 1-in-3 adults by 2050 (Boyle et al. 2010). These data demonstrate that diabetes is a compelling national problem, but the risk of diabetes is not uniform. There are significant disparities associated with diabetes based on race and ethnicity. Minority populations have a higher prevalence of diabetes as compared to non-Hispanic whites (Centers for Disease Control and Prevention 2011; Community Preventive Services Task Force 2011). Hispanics are 66% more likely, and Mexican Americans are 87% more likely to be diagnosed with diabetes (Centers for Disease Control and Prevention 2011). In Albuquerque, New Mexico, diabetes is the sixth leading cause of mortality (New Mexico Health Policy Comission 2009). In the Hispanic immigrant neighborhood where this study was conducted, our preliminary research found that the prevalence of diabetes and pre-diabetes among those sampled was 56%, with 29% of those undiagnosed and unaware of their compromised health status (Mishra et al. 2012).

Although ethnicity is one risk factor (Hanis, Hewett-Emmett, Bertin, and Schull 1991; Samet, Coultas, Howard, Skipper, and Hanis 1988), research has demonstrated a broad range of factors influences diabetes risk. Moreover, the findings of an Institute of Medicine report, (2002) identify the *complicity* of "policies and practices of health care systems…[with]…racial bias, discrimination, stereotyping and clinical uncertainty" (Smedley 2012, p. 993) as core factors in the creation and maintenance of disease and disparity. The etiology of diabetes, then, involves the complex intersection of multiple risk factors, some of which are not traditionally the focus of public health research. This reality has implications for prevention and treatment. Since the cause of diabetes is multidimensional, preventing it or treating it from a purely biomedical perspective is rarely effective; but without a comprehension of the relationship between health and broader social forces that produce disparity, efforts to improve health are not likely to result in meaningful change.

Despite research regarding broader factors involved in disease and disparity, the public health model for diabetes prevention and treatment has tended to continue to focus on getting individuals to change their behavior in terms of diet and levels of physical activity (Diabetes Prevention Program Research Group 2002) or to be "compliant" with prescribed actions and medications for diabetes maintenance (Bahati, Guy, and Gwadry-Sridhar 2012). Expanding the focus to include more expansive factors like historical and structural racism, changing relationships in the international economy that affect employment, housing policy that defines

neighborhood residence, immigration policy, or government subsidies to industrial agriculture, is generally considered to be beyond the scope of study and therefore avoided in public health research. Increasingly though, because of the growing diabetes "epidemic" (Lam and LeRoith 2012) a social determinants of health perspective is seen as more adequate than a focus on individual behavior for addressing diabetes (Fisher, Chesla, Mullan, Skaff, and Kanter 2001; Peyrot, McMurry Jr, and Kruger 1999; Schulz, Zenk, Odoms-Young, Hollis-Neely, Nwankwo, Lockett, Ridella, and Kannan 2005). Groundbreaking research on social determinants of health (e.g., Kawachi and Bruce 2006; Marmot and Bell 2009; Syme and Frohlich 2002) and how "social factors 'get into the body' to cause disease (Syme 2005) helped to focus on disease mechanisms that had not previously been well understood or even imagined. For example, the impact of chronic stress (Cohen, Doyle, and Baum 2006; Kopp, Skrabski, Szé kely, Stauder, and Williams 2007) and the fact that individuals from low-income communities are exposed to higher levels of stress are now recognized as significant and cumulative influences on health and health disparities (Davey Smith 2003; Evans and Schamberg 2009; Raphael, Anstice, Raine, McGannon, Rizvi, and Yu 2003). The social determinants approach acknowledges that health behavior reflects more than individual desire or intention to change (Caban and Walker 2006; Cabassa, Hansen, Palinkas, and Ell 2008; Mendenhall, Seligman, Fernandez, and Jacobs 2010). The extent to which individual action is embedded in contexts external to individual authority and structured by institutionalized relations, environments, and policies is now well-documented in the social determinants literature (CSDH 2008). This has translated into a growing interest in environmental and policy change (e.g., http://www.cdc.gov/prc/about-prc-program/contributions/environment.htm, & http://www.rwjf.org/applications/solicited/ cfp.jsp?ID=20804) and the need to promote "community empowerment" (Brennan Ramirez, Baker, and Metzler 2008) to overcome social determinants as "upstream" strategies for improving diabetes health outcomes.

However, understanding of the social dynamics involved in the mechanisms and pathways of chronic disease continues to lag (Potvin, Gendron, Bilodeau, and Chabot 2005; Trickett 2009). It has become clear that curtailing the alarming rise in diabetes will require a more nuanced understanding of the broader social determinants of health if evidence-guided strategies for individuals at high risk for developing the disease are to be effective. Yet, conceptual frameworks from public health theory, while enlightening in many respects, have not sufficiently embraced the true vision of social determinants thinking (Kawachi and Bruce 2006; Marmot and Bell 2009; Syme 2005; Syme and Frohlich 2002). Current approaches tend to be insufficient for revealing the multi-dimensionality of the relationship between social determinants, chronic disease and health disparity (Chaufan, Constantino, and Davis 2011; Coleman 2011, p. 13). The move toward a perspective on social determinants of health has necessitated a broader conceptualization of factors influencing health, but rarely does research seek to go beyond identifying immediate *barriers* and *promoters* of disease to explore or address the inequitable power dynamics and the root causes involved. Potvin and colleagues (2005) argue that public health operates from this incomplete knowledge base because there is an "acute need for theoretical innovation" (p. 591). Moira (2010) similarly suggests that because theory is not sufficiently incorporated into public health research, the focus fails to go beyond the specifics of what people say or do to developing a coherent interpretation exploring "the meanings and processes associated with the categories of behavior observed" (p. 287)—in other words, an *interpretation* of the data. As such, we have yet to develop a more complete and integrated understanding of the way that health and illness are "produced as a social phenomenon." Like Potvin and colleagues (2005) and Moira (2010), we believe that public health frameworks tend to be under-theorized, and that by expanding our theoretical repertoire to

include conceptual approaches from social theory, we can not only illuminate dynamics underpinning the production of health disparity that are poorly understood in the public health literature, but can offer new perspectives to expand our ability to prevent and reduce health disparity.

Using data collected with a Hispanic, immigrant population in Albuquerque, New Mexico, we apply a *structural violence framework* (Bourgois 2002; Farmer, Nizeye, Stulac, and Keshavjee 2006; Galtung 1969; Scheper-Hughes 1992; Singer 2004) to develop the concepts presented in this article. When analyzing processes related to disease, a structural violence framework takes into consideration the extent to which people's lives are embedded in, reflect, and are limited by institutionalized inequality. Social inequality, whether current or past, is produced by historical processes that create inequitable relationships, environments, and policies, influencing and often governing individual experience. The multi-dimensional nature of social inequality means that its influence in people's lives is cross-cutting; institutionalized inequality affecting one realm of a person's life (*e.g.,* low educational attainment) *spills over* into other dimensions (*e.g.,* health status) (Eide and Showalter 2011; Ross and Wu 1995). Although not commonly employed in public health, a theoretical framework based on structural violence offers a useful tool for analyzing this *spill over*. Using this approach can provide insights for understanding the landscape of diabetes disparities.

Theory: A Structural Violence Framework

Farmer (2005) attributes the term "*structural violence*" to the writings of Latin American Liberation theologians and Johan Galtung (1969; 1990). In the 1960's and 70's, liberation theology gained ascendency in Latin America as Catholic clergy working in impoverished communities throughout the Americas questioned traditional orthodoxy in terms of the role of the church. Liberation theologians espoused a moral imperative for the church to go beyond merely ministering to the needs of the poor to actively undermine and challenge social and economic inequality, and to promote social justice. Catholic bishops in Latin America convened in Medellín (1968) and in Puebla (1978) to "denounce the political and economic forces that immiserate so many Latin Americans" (Farmer 2005 p. 141). The resulting "Puebla document" identified structural forces that allow the "rich [to] get richer at the expense of the poor, who get even poorer" (*ibid.*) (Boff and Boff 1987; Farmer 2005) as the underlying root of social inequality. This is the primary tenet of a structural violence lens.

Academic conceptualization of institutionalized inequality as "*structural violence*" was originally developed in Gultang's (1969) seminal essay *Violence, Peace, and Peace Research* where he identified as violent, processes, actions or causes that result in certain individuals being unable to live according to their own innate skill and capacity-- for their actual lifetime "realizations" to be "*below their potential realizations*" (Galtung 1969, p. 168). When power relations (e.g., class, gender, race), and social institutions (e.g., family, ethnicity, religion) systematically perpetrate and reproduce a lack of actualized potential for some individuals while expanding the actualized potential of others (often beyond that suggested by their own innate skill and capacity), the "violence" becomes ensconced in people's everyday lives as disparity. Although disparity can take many forms, health disparities can be understood as one of the most concrete manifestations of inequity, often determining who will live and who will die—with the poor and immigrants suffering disproportionately. In this context, Farmer, *et al.* (2006) explain that these dynamics "are *structural* because they are embedded in the political and economic organization of our social world; they are *violent* because they cause injury to people (typically, not those responsible for perpetuating such inequalities)" (p. 1686). It is in this context that Farmer (2005), playing on the language of liberation theologians in their argument regarding the

proper perspective and relationship of the clergy and the church to social injustice, suggests that diseases like diabetes have "a preferential option for the poor" (p. 140).

When using a structural violence framework to consider public health contexts, biology and the environment are not treated as independent variables (Singer 2001). From this perspective, we can understand that individual health behavior is circumscribed by structured and institutionalized inequality that limits the ability of individuals to make choices. Limited options then directly affect health outcomes. Individual agency is limited by and contained within the options that are realistically available. In many cases, health-promoting choices are not an option, or they may not represent the most valuable strategy for an individual in the context of other limiting factors—regardless of whether other options are *healthy* or not. Maar, et al. (2011) used a structural violence approach focusing on the circumstances in which Aboriginal people live to understand barriers to diabetes maintenance and treatment. They suggest that "it is important to look beyond the surface and identify the root causes of non-adherence, to prevent the unjustifiable blaming of socio-politically disadvantaged and vulnerable patients for deteriorating their health" (p. 13). Their findings are "compelling" (p. 13). They show that barriers created by social and political marginalization

"put people with diabetes in harm's way by interfering with evidence-based diabetes care, ultimately increasing the risk of rapid onset of complications…The determinants of poor diabetic management uncovered in this research are inseparable from the structural violence exhibited in colonial history resulting in persistent disempowerment, poverty, stress and marginalization of First Nations communities and their health." (p. 13)

Using a structural violence framework to understand health disparities in Albuquerque, New Mexico, we explore how structural forces and institutionalized inequality similarly create the social, emotional, and physical condition that invite and sustain diabetes in a Hispanic immigrant community.

METHODS

Research for this article was conducted by investigators from the *University of New Mexico (UNM)* in collaboration with community partners at *East Central Ministries (ECM)*, a faith-based and social justice-oriented nonprofit organization in Albuquerque that primarily serves Hispanic immigrants. The issue of diabetes was identified as a health priority by members of the community who requested assistance in understanding and addressing diabetes as a threat to the health of their families, and study design reflected a community-engaged approach. The analysis presented here uses data gathered through key community member interviews and focus groups, contextualized by geocoding and data mapping of secondary data sets. The larger study, discussed elsewhere (Mishra et al, 2012; Page-Reeves et al, n.d.) also included a survey and blood analysis based assessment of diabetic status with 100 people.

Study Setting and Population

The site for this research was the *International District* (ID) in southeast Albuquerque, home to a significant Hispanic immigrant population. Located a few miles from the University of New Mexico, the ID is the one of the most diverse neighborhoods in the state, has a large Hispanic population (Childress, 2009), and is the most densely populated sector of the city (U.S. Census Bureau, 2010). Although the cultural diversity of the neighborhood has recently been recognized by some as an asset, the ID is also an area of the city with a reputation for its high levels of poverty (U.S. Census Bureau, 2010), transience (U.S. Census Bureau, 2010), and low educational attainment (U.S. Census Bureau, 2010). In addition, residence in the ID is associated with high levels of diabetes-related hospitalizations and mortality, and childhood obesity. Our preliminary research with ECM in the neighborhood (Mishra et al, 2012) found that

75% of individuals surveyed have a family member with diabetes and 56% of people tested for blood glucose levels were in the range for uncontrolled diabetes/pre-diabetes. Of those, 29% were not aware of their condition.

ECM, our partner for the research, is a non-profit, faith-based community organization operating in the ID. ECM focuses on community, youth, and economic development in the neighborhood with an emphasis on the large Hispanic immigrant population. Besides developing a Community Food Co-op, which addresses some of the food-based needs of individuals in the ID, ECM opened *One Hope Centro De Vida Health Center* in September 2006 to address a community-identified need for better access to quality affordable healthcare. *One Hope* is a low/no-cost clinic providing access to affordable healthcare for people regardless of their health insurance status, and is operated and managed by the community. All of the doctors and medical staff are volunteers, and many are doctors or residents from the *UNM School of Medicine*. *One Hope* is more than just a clinic as it values the holistic health of the community in terms of mental, physical, spiritual, emotional, and social wellbeing. Diabetes care and prevention have been identified as strategic community priorities for 2012 and beyond.

Data Collection & Analysis

Working with the *Office for Community Assessment, Planning and Evaluation* at the *New Mexico Department of Health*, we conducted a secondary analysis of archived data sets including information obtained from the *U.S. Census*, the *New Mexico Department of Health*, *Albuquerque Public Schools*, the *New Mexico Department of Transportation*, *Bernalillo County*, the *City of Albuquerque*, and hospitalization and death records. We geocoded and mapped these data to create maps of the County in terms of multiple dimensions (e.g., demographics, school BMI, pedestrian accidents, violent crime, food outlets, diabetes-related death, health insurance coverage, graduation rates, etc.). We used these maps to contextualize our understanding of risk factors for diabetes and factors that would affect people's food and physical activity behaviors (Mishra,et al, 2012).

Data was also collected through interviews and focus groups. Approval was obtained from the *UNM Human Research Protections Office* prior to the conduct of the research and all participants provided signed informed consent. With the help of the Study Coordinator, who is the Director of *One Hope* and lives in the neighborhood, we identified and recruited six key community leaders in the ID to participate in interviews and eighteen people to participate in focus groups. Three focus groups were held in two sessions each. Interviews and focus groups were conducted at the *One Hope* facility. Participants received a $20 merchandise card to a local business for each interview or focus group session to remunerate them for their time. Interviews were conducted in English by an intern research assistant who took notes by hand. The interview sessions were also audio recorded. Focus groups were conducted in Spanish by the Study Coordinator with support from one of the researchers who also took notes on a laptop computer. Interviews and focus groups used questions from a semi-structured guide that was developed from a review of the literature pertaining to diabetes in Hispanic communities (*e.g.,* Personal Diabetes Questionnaire; Stetson et al., 2011). Questions emphasized understanding people's perceptions of the problem of diabetes, challenges to living a healthy lifestyle, and ideas for diabetes prevention. Questions were open-ended in order to allow participant input to define the direction of the questioning.

RESULTS

In interviews and focus groups, participant narratives conceptualized barriers to diabetes prevention in much broader terms than merely thinking about diet and levels of physical activity. Our analysis of the data revealed opinions and experiences related to people's ability to live a

healthy lifestyle that would prevent diabetes in terms of six themes: (a) Money and cost; (b) Stress and fear; (c) Being physically active is challenging; (d) People eat unhealthy food; (e) Food as social practice; and, (f) People's lack of information (Page-Reeves et al., n.d.). Using a structural violence framework, the issue of *fear* stood out as an important cross-cutting factor that affects how an individual approaches day-to-day living. In interviews with the key community members, as well as in focus group sessions, we identified three main *dimensions of fear* in participant discussion of diabetes and health: (a) Cost; (b) Language, Discrimination and Immigration Status; and (c) Cultural Disconnect. Here we use these dimensions to further conceptualize and explore the theme of fear in relation to diabetes and health disparities.

DISCUSSION
Cost as a Dimension of Fear

As described above, the ID has high levels of poverty with a median household income that is well below national and county average (U.S. Census Bureau, 2010). This disparity can be seen geographically. Our data mapping demonstrates sharp income disparity between the ID and its surrounding neighborhoods. Moreover, the maps show this same geographic pattern for a number of other negative social indicators, including low education attainment, high levels of transience, housing vacancies. This suggests that poverty is tied with many other socio-economic aspects of the community. The same geographic pattern emerges for health issues. Furthermore, our data maps demonstrate that low economic status correlates with high uninsured rates. Because of the economic insecurity, one of the prominent dimensions of fear to emerge during interviews and focus groups was in relation to the financial burden associated with illness. Participants reported that people in this community fear seeking assistance with health concerns or getting sick because of the cost involved, saying *"People are afraid to go to the doctor…they can't afford the bills, can't make the payment…they are scared, afraid"* and *"People are afraid of debt." One Hope* provides health care services on a $15.00 donation basis for doctor's visits, but does not have the capacity to come anywhere close to meeting the healthcare need in the community.

Currently, debate is raging in the U.S. about the sustainability of the healthcare system (Berwick and Hackbarth 2012; Song and Landon 2012). One of the biggest barriers to improving health being discussed on a national level is cost (Harrop 2012; Hensley 2012). There are currently more than 50 million Americans without health insurance, or one in six who are not receiving adequate healthcare (Wolf 2010). In our study, participants discussed how cost limits access. In the ID, people do not go to the doctor because given their limited income, individuals are forced to choose between paying the doctor (whether through co-pay if they have insurance or more likely, by paying out-of-pocket for services if they do not) or paying essential bills for food, electricity, water, gas and rent. Moreover, individuals without health insurance will often wait until *"the last minute,"* before going to the doctor. The result is that health problems go untreated and undiagnosed, and tend to become more acute, and ironically, more expensive.

Participants also described how parents put their children's health first when they neglect their own medical concerns in order to be able to afford to pay for milk, bread, clothing, and shelter. All of these expenses sustain a family and take precedence over individual potential health problems. *"Although diabetes may kill you someday, it's not going to kill you today,"* one community member stated. While the consequences of uncontrolled diabetes may not be imminent, the potential consequences of not paying the rent and becoming homeless is an immediate possibility. Because few people have a medical home with an established primary care provider, the emergency room becomes a default "clinic" for all types of healthcare.

Emergency room visits are expensive, and people are often unable to pay their bills. Interest accrued on unpaid bills can quickly become more than the original expense. In addition, participants reported that is common for bills to be sent in English and people who do not read or speak English are not able to understand what the bill is about or what they need to do to settle it.

As such, the fear of going to the doctor is much more complicated than concern over what unpleasantness may be entailed in a particular treatment. Among families living in poverty, the cost of healthcare causes a level of stress that people described as a *fear*. This fear is created, not by the illness of diabetes itself, but by the structural relations defining the economic condition of a low-income, immigrant community that intersect with the incidence of chronic disease. Without resources, people are unable to obtain the healthcare they need to treat or prevent diabetes. This disparity is then exacerbated by the stress and often debilitating fear caused by the financial burden associated with illness or with trying to stay well. The fear itself then nurtures and encourages further health disparity nicely captured in the comment by one participant that, "*That's why there's a lot of depression in this community…they don't have the resources to pay for the basic needs (especially if you're undocumented)…it's difficult asking for help.*" The fear of cost can be understood as a form of *violence* that is not something experienced by people who have health insurance or sufficient resources. Like chronic disease, certain dimensions of fear can be seen to have a "*preferential option for the poor*" (Farmer 2005, p. 140).

Language, Discrimination & Immigration Status as Dimensions of Fear

Another prominent dimension of fear reported by participants was particular to an immigrant community. The ID is so-named because it is one of the most diverse neighborhoods in the state (Childress, 2009). The data maps we created revealed a high percentage of foreign-born residents in the International District, and a statistically significant number of which are not U.S. citizens, and that a high percentage of Spanish speakers in the ID do not speak English very well (U.S Census Bureau, 2010). In the past, this diversity was associated with negative social and economic conditions and the neighborhood and was viewed through a lens of *blight*. Over the past few years, this diversity has come to be recognized by some as an asset, but challenging mainstream views of the neighborhood has been difficult and stereotypical negative discourse and attitudes remain common.

Participants in our study expressed strong sentiments regarding discrimination that immigrants face on multiple levels on a daily basis. They feel that people with a Spanish accent or who lack English-speaking skills are discriminated against in institutions like doctor's offices, clinics and hospitals. ECM's *One Hope* clinic caters to the needs of the immigrant community and attempts to address these concerns by providing professional translation in the clinical setting. In addition, patients all receive an "exit interview" ("*salida*") by a Spanish-speaking community health worker who goes over instructions and health information that the patient has received from the provider. However, care at *One Hope* is not the norm in Albuquerque. Participants described, in detail, the discrimination that they commonly experience.

Discrimination often takes the form of tacit disapproval on the part of the receptionist in healthcare settings who makes people feel that they are a burden or that they should be ashamed of their inability to communicate. Almost all of those interviewed reported numerous instances when receptionists at various health clinics in Albuquerque refused to speak Spanish to patients, often literally telling them to speak English because "*you're in America now*." One participant said, "*…they feel that discrimination…why do you need help, you aren't supposed to be in this country…so they are afraid and don't ask [for help].*" The attitudes of institutional actors in healthcare settings can become what Larchancé (2011, p. 859) called "intangible mechanisms of creating or reproducing population hierarchy" in relation to immigrants and ethnic difference.

She argues that this influences social practices through what she defines as "powerful '*subjectivation'* effects" that are both psychological and political, influencing and shaping the behavior of immigrants and institutional actors in a dynamic of hierarchy. This process, in turn, contributes to the construction of immigrants as *undesirables*.

Although hospitals have policy regarding the provision of professional interpreters, participants said that they are still made to feel guilty—as if it is somehow their fault that they need this service. At the same time, participants reported a dearth in bilingual support at clinics. This is especially problematic in a state with such a large Spanish-speaking population. One of the interviewees, who also has a job as an interpreter at a large hospital, indicated that the interpretation provided is often very poor. In one example from a psychiatric out-patient clinic, a psychiatrist asked the patient if they had been unable to *concentrate* recently. The interpreter, a native Spanish speaker and fluent in English, asked the patient if they had been *constipated* recently. The patient responded that they had not been constipated, although they had been suffering from an inability to *concentrate*. This would be funny if it were not so tragic. The explanation for this critical mistake given by the interviewee was that the medical interpreters are generally disinterested and not fully-invested in what they do—further reflecting structured inequality in employment options for individuals who while they may be bi-lingual are not credited with other skills meriting a higher salary. For good reason then, people who have an accent when they speak English fear being made to feel stupid or incompetent, and people who cannot speak English are afraid of finding themselves in a situation where they cannot communicate their symptoms, or understand what people are saying or what they are being told to do. These language/discrimination-based fears are often enough to make people refuse to go out to seek assistance until their health problems become acute.

People's language-related fears are a reflection of experience, but fear reported in relation to discrimination is more than merely a concern over language proficiency. Many of the immigrant households in the ID have members with problematic immigration status. The number of individuals in the ID who do not have immigration documents ("*undocumented*") is high. Participants felt that this fact tinges the experience of people who have an accent or difficulty speaking or understanding English. They reported that the level of care and treatment that Spanish-speakers receive is *different* from that of people who are presumed to be citizens. As a result, people fear being singled-out for different treatment or being treated as if they are *illegal*, whether they are or not. By definition, being illegal implies that they are bad people. One participant expressed how this difference in treatment is perceived, saying *"These people, even when in the hospital or the waiting room, there's a big sign that says we're not going to discriminate anybody or whatever…[but] the immigrant people…I've seen so many, many differences in the way that they treat them, especially with access in the system."* Another, in a more pointed description said,

> *"and I hate to say it, but we're a racist, xenophobic society that refuses to deal with immigrants…we can't manage to provide healthcare for everyone that is a citizen, let alone those that are not …until [the hospital system]really decides to quit discriminating against immigrants and indigent folks in general in our community…it's going to be a huge barrier."*

Lechanche (2012) reports that because of these dynamics, immigrants can feel a sense of intimidation and fear in institutional health contexts that can lead them to adopt strategies downplaying their real health-related needs and concerns in an attempt to make themselves seem more "*deserving*" of assistance (p. 861). Belliveau (2011, p. 41), calls these behaviors, "strategies of acquiescence" that immigrants use to balance their needs with the realities of discriminatory environments and exclusionary institutional policy.

The fear around *illegality* expressed by participants is partially an abstract concern with the discriminatory treatment involved, but for individuals who lack documents or have family members without documentation, the fear is more concretely about being *discovered*. Deportation is an ever-present reality for people living in the shadows because they lack legal immigration status. This threat, especially when combined with the other dimensions of fear, becomes virtually paralyzing for many people in terms of seeking assistance with health problems. Many of those who lack documents do not feel comfortable or safe going to a clinic or to the emergency room. Discussing the fear associated with lacking documents and demonstrating the cross-cutting nature of fear, one participant who works for an agency that serves immigrants said, "*Our clientele run on fear because of their documentation status…if a bill collector is bugging them, then they fear INS [Immigration and Naturalization Service] may be looking over the bill collector's … shoulder… people are really fearful.*" Participants described a local medical provider's aggressive questioning of patients (or, in this case, it was referred to as "*interrogation*"). It was reported that this physician routinely asks patients about their legal status. If the patient is an illegal resident, the physician asks to know how the patient entered the country (e.g., via a "*coyote*"), how much it cost the patient and who they paid. This line of questioning is viewed by participants as intrusive and inappropriate in a medical environment. Knowledge of encounters like this, especially with physicians who are proverbial "gatekeepers" in the system, spreads like wildfire throughout the community. People become afraid that at best, the doctor may be making erroneous assumptions about their immigration status, or at worst, be trying to sniff out and report immigrants without documents.

Discrimination against immigrants and minorities is a deeply rooted social construct that is embedded in American political and social discourse (Chavez, 2008). Combating such embedded discourse in a medical context is difficult, especially in times of economic downturn when immigrants become convenient scapegoats for a variety of social ills. The economic and social burden of "*criminal aliens*" is a common theme in the media, while others portray immigrants as an economic and social danger (Jordan, 2010; Willson, 2010; Wolf, 2010). In caricaturing *all* immigrants as illegal or potentially illegal, and by conveniently ignoring the fact that the vast majority of immigrants without documents come to this country to work (and generally they work "hard") rather than to rape and pillage, mainstream images portray immigrants as a danger to society (Anderson, 2006; Chavez, 2008). This dynamic effectively institutionalizes discriminatory treatment and disparities in access to healthcare for immigrants, while ensconcing fear into people's daily lives. Larchanche (2012) describes how immigrants exist within a "climate of fear [that is] tangible" (p. 862), extending even to those who provide services and help to the undocumented. Viruell-Fuentes, Mirand and Abdulrahim (2012) suggest that understanding how complex factors such as these influence immigrant health requires shifting the focus away from the individual to an analysis of multiple dimensions of inequality and how they intersect to produce health disparities.

Cultural Disconnect as a Dimension of Fear

The third dimension of fear we identified in participant narratives has to do with concerns described by participants about their inability to discuss the fact that they use "traditional" remedies to cure or treat some of their health problems, including diabetes. Walton (2009) describes this type of conflict between patients and providers regarding non-medical or alternative medicine as "*cultural disconnect*." Many of the participants reported that it is common for people to use a variety of medicinal herbs or other alternatives to prescription medication to treat their health problems. For diabetes, it is not unusual for people to use herbs or particular foods to lower blood sugar. A number of participants recounted the story of a man who was selling a type of "bark" from Mexico to cure diabetes that people could take in the

form of a tea. The price he was charging for the bark was extremely expensive, but many people bought it. Not surprisingly, taking the tea did not have the desired effect, and participants reported that people ultimately felt swindled by a charlatan. Participants said that people are hesitant to tell their provider about the fact that they take or use these products or that they would like to know more about the effects of taking them. This *cultural disconnect* over the use of these alternative medicines is a common experience for immigrants in a healthcare setting.

Doctors trained in a bio-medical model often have little patience for or a misunderstanding of alternative medicine (Farmer, 1999; Farmer, 2005; Poss, Jezewski, and Stuart, 2003; Singer, 2004; Walton, 2009). Yet in many cultures, including that of many Mexican immigrants, alternative medicine can have important cultural dimensions, and at the same time, supplement medical treatment (Astin, 1998; Niforatos, 2012; Poss, Jezewski, and Stuart, 2003; Rivera, Ortiz, Lawson, and Verma, 2002). Participants in our study described their own conviction that these remedies and alternative treatments are effective, more trustworthy and less likely to have damaging side effects than prescription medication (Poss, Jezewski, and, Stuart 2003; Rivera, Ortiz, Lawson, and Verma, 2002). They also discussed the social obligation they feel to try a remedy if a relative or close friend recommends it.

At the same time, individuals who use alternative medicine routinely hide their use of alternative remedies and treatments from their provider. Patients often feel, either from previous experience or from the experience of others, that their physician will "*scold*" or ridicule them for using alternative treatments that the provider believes to be irrational. As a result, many do not tell their healthcare provider that they are using alternatives to prescribed treatment. (Poss, Jezewski, and Stuart, 2003; Rivera, Ortiz, Lawson, and Verma, 2002). One participant said, "*A lot of our community members are afraid to tell their providers that they take tea (alternative medicine) because of problems that have happened in the past…people don't know, so they are afraid of what [their provider] will say.*" The perceived ethnocentrism on the part of the healthcare provider creates a *stigma* for patients who may have a different worldview. Sociologist Erving Goffman (1963,) defined stigma as "the process by which the reaction of others spoils normal identity" (p. 3). The potential negative reaction of the healthcare provider towards a patient in relation to the causes of and cures for disease, or the providers' questioning of the rationality of alternative treatments can "spoil the normal identity" of the patient. In other words, this *cultural disconnect* can make them feel that something they value is seen as wrong, silly or irrational by others. This stigma produces a (sub-)conscious fear on the part of the patient regarding their relationship with their provider, negatively influencing the care they receive. Yet, the consequences of *cultural disconnect* can be more dire than fear of social stigma. One participant reported an instance when a healthcare provider notified Child Protective Services because of marks on a child's arms. As a result, the child was removed from the home. Although temporary, this experience was traumatic for the child, the parents, and the community. A cursory knowledge of the community could have prevented an event like this from occurring; the marks on the child's arm were from the application of a traditional remedy to treat the child's sickness rather than the child abuse that was alleged. Seen in this light, there may be good reason to hide the use of alternatives to biomedical treatment.

Cultural competency is a well-documented issue in the literature on health disparities (Betancourt, Green, Carrillo, and Ananeh-Firempong, 2003; Betancourt, Green, Carrillo, and Park, 2005; Farmer, 1999; Hirsch, 2003; Ikemoto, 2003; Kleinman and Benson, 2006). However, it is common for providers to be unaware of or to lack understanding of the realities of the lives of their patients, as in the example given above. Farmer (1999; 2005) and Singer (2001; 2004) highlight how important it is for providers to understand the history, political economy, and culture of the population that they serve. In one poignant example, it was common for

patients on the central plateau of rural Haiti not to finish a full-course of tuberculosis (TB) treatment. Practitioners attributed this to local beliefs related to alternative medicine held by followers of *Voodoo*. Farmer and colleagues (1999) conducted a study to determine if this was the case. What they discovered was that non-biomedical beliefs of the etiology of disease had no impact on whether a patient finished the full-course of TB treatment; rather, *access* to the TB medicine and having support from community health workers to monitor patients were the key determinants of whether the patients were "compliant." Elsewhere, Farmer and colleagues (2005) observe that "those least likely to comply are usually those least able to comply." Understanding the history, political economy, and culture of Haiti allowed the Harvard-affiliated, non-profit health and social justice organization, *Partners in Health*, to subsequently effectively treat TB. It is common for providers to blame noncompliant behavior on cultural dictates that are unintelligible to them as outsiders (e.g., *Voodoo*), but this approach under-appreciates both cultural dynamics at work and the influence of contextual factors. Moreover, the culture-as-problem framework for understanding health disparity often merely serves to legitimize and underscore narratives that devalue the poor and communities of color as irrational and therefore *deserving of what they get*.

The fear experienced by Hispanic immigrants in the ID related to *cultural disconnect* is a reflection of larger inequities within the system. In the ID, provider *cultural incompetence* and the resulting *cultural disconnect* have the effect of making patients fear discussing alternative treatments, whether they take them or not. The fear that results from *cultural disconnect* reduces a patient's ability to receive proper medical treatment and further puts the patient as risk when they do seek care. When patients hide their use of or belief in alternatives to provider-based medicine and do not tell their healthcare provider what alternative treatments they are using, they risk having a reaction with pharmaceuticals prescribed by the physician. The violence perpetrated upon individuals with alternative beliefs and behaviors in terms of stress, lack of attention to medical problems and the potential for serious drug reactions reflects structural inequality, and reproduces and accentuates existing health disparity.

CONCLUSION
Structural Violence and Fear

Although diabetes is a national health problem, the burden of the disease and its consequences are not shared equally. Statistics show that Hispanics are at particular risk. While we know how to prevent diabetes through a healthy diet and regular physical activity, and how to maintain the health of people with diabetes through a regimen of care from a provider, we have not been able to develop meaningful strategies to encourage prevention or "compliance", especially in contexts of disparity. Although the social determinants of health approach for understanding chronic disease has improved our conceptualization of how individuals are embedded in contexts and environments that influence their ability to make healthy choices, live a healthy lifestyle, and seek or have access to healthcare, we continue to lack a more integrated understanding of the nature of social practices that impact health and how social determinants operate to produce health disparities. Unpacking the dynamics of this process requires further expanding our theoretical repertoire.

We proposed that applying a structural violence framework to understanding diabetes health disparities in a Hispanic immigrant community in Albuquerque would provide significant insights into the processes that produce and encourage disparity. A structural violence framework takes into consideration the extent to which people's lives are affected by institutionalized inequality, influencing and often governing individual experience. Political, economic, and social inequalities limit the personal agency of an individual to live a healthy life

or to seek care. Attention to this type of cross-cutting factor is not commonly employed in more theoretically shallow public health analyses of *barriers* and *promoters* of disease. This study highlights the importance of moving beyond uni-dimensional approaches to be able to capture the dynamics of social practices that operate across multiple dimensions of people's lives in ways that may not immediately appear related to *health*. We demonstrate how structural forces simultaneously directly inhibit access to appropriate healthcare services and create fear among immigrants in Albuquerque, acting to further undermine health and nurture disparity. Although fear is not normally directly associated with diabetes health outcomes, in the community where we conducted this study participant narratives discussed fear and health as interconnected. People's everyday lives are framed by fear. For residents of the ID, fear is both a psychological barrier for those seeking access to healthcare services and a further burden of stress that negatively affects their health. Institutional and social inequalities, poverty, discrimination, immigration status issues, and cultural bias, create an experiential landscape that generates fear. People are afraid because they recognize their inability to deal effectively with costs, language barriers, immigration documentation requirements, and the cultural incompetence of others that makes people feel inadequate. Fear is pervasive and multidimensional.

Our study corroborates what Singer (2001) observed of social inequalities and health, namely, that structural forces create the social, emotional, and physical conditions that invite and sustain disease. Among Hispanic immigrants in the ID, fear is one of these conditions. Using a structural violence framework to conceptualize the multidimensionality of this fear, we can see how structural violence operates to further limit the personal agency of individuals already significantly constrained by structural inequality. Physician-anthropologist Arthur Kleinman (2006a) observes that a limit in personal agency causes an "enervating anxiety…[an] existential fear that wakes us at 3 a.m. with night sweats and a dreaded inner voice, that has us gnawing our lip, because of the threats to what matters most to us." This type of *existential fear* is palpable in the ID, dramatically undermining the opportunity for immigrants at risk for diabetes to be healthy. Given the consequences of diabetes, the result is ultimately a matter of life and death.

In this study, we aim to use our research to "ask questions about the assumptions built into public health studies…as a way to understand [the] embodied reality" (Coleman 2011, p. 13) of inequality. By expanding our theoretical repertoire to include frameworks from social theory, we are able to reveal dynamics underpinning health disparity in an immigrant community that are not commonly the focus of attention in public health research or interventions. As part of our analysis of structural violence in the landscape of diabetes in the ID, we identify the multidimensionality of *fear*. We give voice to what *matters* to individuals who have been made to seem invisible by a "regime of disappearance" (Goode and Maskovsky 2001, p. 17) created through a paradigm of research that tends to ignore and maintain a convenient ignorance of the structural forces that institutionalize inequality and produce and maintain health disparity. This "regime" makes health disparity appear as an unavoidable consequence of the natural order of things, reflecting risk factors internal to or specific to individuals, and allows the silo-ing of health from other dimensions of life. In this regard, the structural violence lens helps to reintegrate our understanding of health by illuminating and emphasizing the extent to which the dynamics of disparity are structured by broader political, economic and social forces. Deeper theorizing allows us to activate our conceptualization of how the social determinants of health *operate* rather than merely acknowledging that they *exist*.

Like the IOM report (2002) on racial and ethnic disparities in health care, the data from our study demonstrate that effective diabetes prevention in communities like the ID requires that

we move beyond the focus on *barriers* and *promoters* that is common in public health research; if we are to reduce or eliminate diabetes health disparities, we must address factors previously assumed to be *beyond* the focus of public health, such as fear and its multiple root causes. Yet this means moving outside of the *comfort zone* created by the positioning of health research as separate from or above the need to address structural inequality. Those of us who attempt to approach the work of public health from a broader perspective are routinely instructed that such a focus is the purview of other disciplines, too far afield from health-related concerns, or too *political*. The perspective common in public health research is nicely summed-up in the experience of one of the authors who was told by a colleague leading a project that it was not possible or appropriate to think about or investigate *poverty* in relation to the public health issue that was the focus of the research, despite the fact that the community of study was characterized by significant levels of poverty and health disparity that had provided the central rationale for the research. Given the need to address the health disparities that are destroying lives in the ID and similar communities, public health as a discipline can no longer legitimately espouse an interest in addressing health disparity through environmental and policy change or "community empowerment" while generally being unwilling to think about non-health related factors and dynamics that generate disparity. Of course, this shift is extremely challenging given the epistemological tendency in public health to narrow the focus of research in order to improve the *scientific* quality of the variables, the concern that funders will find a broader focus *distasteful*, and the discomfort that many researchers (and Americans in general) feel about discussing structural inequality, its roots and our own potential complicity or participation in the creation and maintenance of privilege and disparity. Without this paradigm shift, however, we *fear* that hoped for improvements in health equity delineated clearly in the Final Report of the Commission on Social Determinants of Health from the World Health Organization (CSDH, 2008) will not be possible. Incorporating social theory (such as the structural violence framework utilized in the analysis presented here) into the way that we conceptualize public health contexts and the way that we view the purpose and focus of our own research helps to move us toward embracing a new research paradigm challenging the *status quo*. This shift improves the potential for our work to meaningfully reduce and eliminate disparities such as those experienced in relation to diabetes by immigrants in the ID.

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