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An Integrated Approach to Diabetes Prevention: Anthropology, Public Health, and Community Engagement

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Abstract

Diabetes is an enormous public health problem with particular concern within Hispanic communities and among individuals with low wealth. However, attempts to expand the public health paradigm to include social determinants of health rarely include analysis of social and contextual factors considered outside the purview of health research. As a result, conceptualization of the dynamics of diabetes health disparities remains shallow. We argue that using a holistic anthropological lens has the potential to offer insights regarding the nature of the interface between broader social determinants, health outcomes and health disparity. In a primarily Hispanic, immigrant community in Albuquerque, New Mexico, we conducted a mixed methods study that integrates an anthropological lens with a community engaged research design. Our data from focus groups, interviews, a survey and blood sampling demonstrate the need to conceptualize social determinants more broadly, more affectively and more dynamically than often considered. These results highlight a need to include, in addition to individual - level factors that are traditionally the focus of public health and more innovative structural factors that are currently in vogue, an in - depth, qualitative exploration of local context, social environment, and culture, and their interactions and intersectionality, as key factors when considering how to achieve change. The discussion presented here offers a model for culturally situated and contextually relevant scientific research. This model achieves the objectives and goals of both public health and anthropology while providing valuable insights and mechanisms for addressing health disparity such as that which exists in relation to diabetes among Hispanic immigrants in New Mexico. Such an approach has implications for how research projects are designed and conceptualizing social determinants more broadly. The discussion presented provides insights with relevance for both disciplines.

Keywords

Anthropological Lens, Community Engagement, Diabetes Prevention, Hispanic Immigrants, Health Disparity, Integrated Approach

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Introduction

The Challenge of Chronic Disease and Health Disparity

Diabetes is now an epidemic health crisis in the U.S. (Boyle, Thompson Gregg, Barker, & Williamson, 2010; Centers for Disease Control and Prevention [CDC], 2011a), with low-income/low-wealth communities of color at particular risk (CDC, 2011b). Although we know how individuals can prevent and manage diabetes (Diabetes Prevention Program Research Group, 2002), prevention and management in real life settings have proven challenging (Caban & Walker, 2006; Trickett, 2009). In the public health arena, researchers have now recognized that part of the solution is to expand the focus from individual behavior to include the social determinants of health (Thomas, Quinn, Butler Fryer, & Garza, 2011; Trickett et al., 2011). Researchers have written extensively on diabetes in terms *barriers* and *promoters* for treatment and prevention (Heideman et al., 2011; Thorpe et al., 2013), yet insufficient progress has been made in our ability to understand and address the multidimensional nature of diabetes risk. Conceptualization of social determinants in the public health literature is too often compartmentalized, under-theorized and shallow. Research approaches with the capacity to provide insights into the synergistic dynamics of processes that produce or protect against chronic disease have not been formulated. The urgency of our need to understand complex processes that influence health is accentuated by the realities of health disparities that diminish and destroy the lives of individuals, families and communities.

Expanding Conceptualization of the Social Determinants

Responding to the crisis of chronic disease requires a qualitatively different research enterprise. A more comprehensive approach that expands conceptualization of how the social determinants of health *operate* rather than merely acknowledging that they *exist,* will allow us to develop a more intricate and meaningful portrait of the lived reality of the health issues we study and care about. We believe that although often under-appreciated in health research, an anthropological lens offers a valuable tool for improving our understanding of these dynamics. An anthropological perspective can reveal abstract social and cultural concepts, articulate them with the local context, and synthesize domains often treated as independent or irrelevant in health research. Combining the epistemological benefits of this conceptual holism with a research design that responds to community-identified concerns, and engages community members in developing an understanding of issues and co-creating innovative solutions holds great promise.

Discipline Politics

However, the view of this sort of research from within anthropology remains problematic. While anthropology as a discipline has struggled to redefine itself to ensure relevance with respect to pressing social issues (Comaroff, 2010; Peacock 1997; Shankland, 2012; Singer & Erickson, 2011), medical anthropologists have generated cutting edge research that is both theoretically grounded and socially significant (e.g., Dressler, 2001; Farmer, 2005; Green, 1998; Mendenhall, 2012; Mendenhall, Seligman, Fernandez, & Jacobs, 2010; Singer & Baer, 2007;), often incorporating methods and approaches from other disciplines. Despite the important contribution that this work has made to our knowledge of health, research that is conducted with concrete objectives to improve health outcomes is often disdained within academic anthropological circles for being too *applied*. This

perspective is epitomized by the experience of a colleague who was accused by other anthropologists of "going over to the dark side" because she was involved in a research project that involved a health promotion intervention. At the same time, rather ironically, despite moves to incorporate basic social and cultural dynamics as a focus in health research (e.g., http://oppnet.nih.gov/about-mission.asp) and extensive discussion of the need for more qualitative data (*e.g.,* Brinkman, 2012; Edwards, 2012), it remains challenging to convince funders and reviewers to provide support for research using anthropological approaches which are seen by mainstream public health institutions as too "fuzzy" to be "real science."

Modeling an Integrated Approach

In a primarily Hispanic, immigrant community in Albuquerque, New Mexico, where residents are concerned about diabetes and interested in figuring out how to prevent it, we conducted a study that pursues an approach that integrates an anthropological lens with a community engaged research design. Below we present our findings and discuss our experience with conducting this study. We believe that the research presented here offers a model for culturally situated and contextually relevant *scientific* research. This model achieves the objectives and goals of both public health and anthropology while providing valuable insights and mechanisms for addressing health disparity such as that which exists in relation to diabetes among Hispanic immigrants in New Mexico. Such an approach has implications for how research projects are designed and contributes to our ability to conceptualize social determinants more broadly. Insights from this material have relevance for both disciplines.

Literature Review

Diabetes and Health Disparity

About 25.8 million children and adults, or about 8.3% of the population of the United States have type II diabetes (CDC, 2011a). However, the risk of diabetes is not uniform. Individuals from racial and ethnic minority populations are disproportionately affected by diabetes and its consequences (CDC, 2011a, 2011b). A significant disparity exists in relation to diabetes outcomes between populations of color and non-Hispanic whites. For example, the prevalence of diabetes among Hispanics is almost twice that of non-Hispanic whites (9.8% vs. 5%) (CDC, 2011b; National Diabetes Education Program, 2011). Moreover, Hispanics are 50% more likely to die from diabetes-related health consequences than non-Hispanic whites (CDC, n.d.; Office of Minority Health, 2010). In Albuquerque, New Mexico where we conducted the research for this article, diabetes is the sixth leading cause of mortality (New Mexico Department of Health, 2009). In the Hispanic immigrant community where data for this article was gathered, our preliminary research suggests that the prevalence of diabetes and pre-diabetes may be as high as 56% (Mishra et al., 2012).

The Challenge of Prevention

These data are particularly disturbing because there are evidence-based guidelines for preventing or delaying diabetes among individuals at high risk for developing the disease. People can reduce their risk for or avoid developing diabetes through regular physical activity and consuming a low fat and low calorie diet (Diabetes Prevention Program Research Group, 2002). However, evidence-based interventions have not been effectively translated into widespread practice, especially among culturally diverse populations. Designing diabetes

prevention interventions for use in communities is challenging because it requires understanding specific community dynamics to which researchers are rarely privy, and incorporating cultural constructs more centrally than commonly employed in research design (Frolich & Potvin, 2010; Trickett, 2009). Even more complicated is successfully implementing an initiative in a community where health disparities are greatest. The nexus of social, economic, and racial inequality associated with health disparities creates multiple, simultaneous pressures that make it difficult for prevention to be a meaningful part of people's lives (Caban & Walker, 2006; Cabassa, Hansen, Palinkas, & Ell, 2008; Mendenhall et al., 2010).

The dilemma entailed in developing effective prevention programs for use in communities, especially communities affected by disparities, exists not only in relation to diabetes, but is a central challenge for community health promotion work in general. To overcome this challenge, the public health paradigm is currently shifting to accommodate innovative approaches for understanding community perspectives and for designing and implementing interventions (Trickett et. al., 2011). Although not everyone is yet on board with the emerging paradigm, accepted approaches are giving way to new concerns with complexity and intersectionality in health disparities research (Burkner, 2012; McCall, 2007; Rogers & Kelly, 2011; Schulz & Mullings, 2005; Thomas, et al, 2011; Viruell-Fuentes, Miranda & Abdulrahim, 2012; Williams & Sternthal, 2010; Winkler & Degele, 2011). As Frolich and Potvin (2010) suggest, we need interventions that address the way that social practices are produced if we are to get beyond the lukewarm results of prevention interventions in communities to have a meaningful impact on reducing disparities. To get there, we need different approaches, different methods and a different epistemological understanding of the problems we purport to address. Qualitative, nuanced, in-depth study that engages members of the community to participate in the research has been identified in the literature as a strategy with promise for obtaining richer perspectives on community health issues and for designing interventions with a higher likelihood of success (Mcintyre, 1997; Trickett et. al., 2011; Williams, 2003). Yet in health research, "qualitative" is primarily understood as a set of methods rather than as a distinct research enterprise (Lambert & McKevitt 2002; Morse, 2006; Wuest 2011). We believe that this lapse contributes to a continuing lack of understanding of basic social, cultural and behavioral processes that require a different lens.

Anthropological perspectives and approaches have been suggested as one avenue for examining these dimensions of health (Bandyopadhyay, 2011; Campbell, 2010; Krumeich, Weijts, Reddy, & Meijer-Weitz, 2001; Lambert & McKevilt, 2002;). Ferzacca (2012) and Smith-Morris, Morales-Campos, Alvarez, and Turner (2013) believe that anthropology is particularly well suited for analyzing the complex dynamics of diabetes. However, although the anthropological literature on diabetes is extensive and dynamic (Ferzacca, 2012), anthropological perspectives are often under-appreciated or mis-used in mainstream health research (Krumeich et al., 2001; Lambert & McKevitt, 2002). For example, anthropologists have explored health beliefs and conceptual models of illness, demonstrating how differences in the way that providers and patients or distinct population groups understand the etiology and progression of diabetes significantly impact both prevention and management of the disease (Mercado-Martinez & Ramos-Herrera, 2002; Schoenberg, Drew, Palo Stoller, & Kart, 2005; Weller et al., 2012). Yet mainstream health research has tended to adopt these insights through a "health behavior" framework that can exaggerate individual "agency" while overlooking or ignoring the extent to which culturally based models for understanding and dealing with disease are contextual (Clark, Vincent, Zimmer, & Sanchez, 2009). Individual explanatory models of health must be seen as "situated in a structural lifework"

that influences what people believe and how they see the world (p. 384). What is lacking is a conceptual framework for making this connection.

Similarly, anthropological studies have shown how core cultural values and concepts influence these dynamics and processes (Flores, 2000; Mendenhall et al., 2010; Marin & Marin, 1991; Mendenhall, 2012; Sabogal, Gerardo, Otero-Sabogal, Vanoss Marin, & Perez-Stable, 1987). The idea that culture influences health has been accepted by the broader health research community, yet the tendency has been to "bundle" cultural constructs or to use them as proxies for understanding the health behavior of populations that only superficially represent a coherent grouping (Smith Morris et al., 2012). Diabetes health among Hispanics is often interpreted using a framework that emphasizes cultural constructs identified by anthropologists as core cultural values, including: *familismo*, a high value placed on relations within the extended family (Anderson, et al., 1998; Flores, 2000); *simpatico*, a high value placed on maintaining pleasant social relations and avoiding conflict (Marin & Marin, 1991; Flores, 2000); and *reciprocidad*, the importance given to balancing the acts of giving and receiving (Simoni & Perez, 1995). Yet nuanced anthropological insights about the contingent nature of these values and how they are mobilized in individual contexts is often lost in their application in mainstream health research. For example, Smith Morris et al. (2012) show us the importance of the classic anthropological tenet regarding the need to differentiate between expressed ideals and actual behavior in how constructs like *familismo* are deployed. People routinely operate on the basis of multiple, competing values and ideas (*e.g.,* family members are wonderful parts of our lives, family members are a disruptive and meddling part of our lives). This means that we need to consider the context in which values are expressed in order to understand what Hunt, Valenzuela and Pugh (1998) describe as "provoking" factors that influence health outcomes. As Lambert and McKevilt (2002) point out, anthropologists do not assume that cultural concepts and practices are normative or universal. It is incumbent upon the researcher to investigate the context specific nature of social process and "situate" the life of the participant (p. 211).

Agency or Structure?

The importance of context has recently become more apparent in public health discourse. Public health researchers have recognized that the medical model approach to diabetes prevention focusing on individual behavior change is insufficient. Getting individuals to change their behavior is more complicated than merely moving an individual along a continuum of self-efficacy toward healthier decision-making (Prochaska & DiClemente, 1984). People's lives exist within contexts that influence individual behavior and impact their ability to live a healthy lifestyle. The extent to which these contextual influences are structured by institutionalized relations, environments and policies that are external to individual authority is now well-established in the growing literature on the social determinants of health (Braveman, Egerter, & Williams, 2011; Koh et al., 2010). Increasingly, it has been suggested that part of the solution is to move beyond a focus on individual behavior to concentrate on transforming community environments and policies that promote unhealthy behaviors so that the "default" choices that people make will be healthy ones. Not surprisingly, many of the "defaults" in communities affected by disparities tend to be unhealthy ones—a fact that underscores the injustice. This approach is now the mantra of funders, with programs like the CDC's "Putting Prevention to Work" and "Community Transformation," and the Robert Wood Johnson Foundation's "Healthy Communities Grants," that are attempting to create healthier environments and policies that will promote healthy lifestyles. The environmental and policy change approach is now rife in the literature on prevention (Bunnell et al., 2012; Lamichhane et al., 2012).

This change from a focus on individual behavior to policy/environment is a theoretical improvement to the extent that it better reflects the fact that individuals are embedded in contexts and that their choices are structured by factors and forces over which they have little control. However, although the policy and environmental change approach has great potential, it is apparent that diabetes prevention is not an "either – or" proposition. Individual choices (*agency*) are made in a context of options limited by environment/policy (*structure*), but the reality of how these work together is much more complicated than merely locating people in a context. The emergent or dialectical nature of health behavior continues to defy definition (Dressler, 2001). Developing a more integrated notion of how social determinants operate that encompasses a broader range of factors has proven to be elusive. Although we might know what the components of a diabetes prevention intervention look like (e.g., improved diet, more physical activity, improved access to physical activity and healthy food, policies to promote healthy eating and active living, and social support), no clear model has been developed for figuring out how to make these things happen on the ground, in concert, and in a manner that is meaningful for people and financially feasible, especially in communities with disparities. We believe that an anthropologically inspired multi-level, multi-dimensional and contextually situated approach that engages community members and gives voice to their ideas and concerns offers the best hope for improving health outcomes.

Methods

Research Design

Researchers at the University of New Mexico (UNM) collaborated with East Central Ministries (ECM), a nonprofit organization located in the International District (ID) of Albuquerque, on a community-driven and community-engaged study to explore local diabetes-related needs, experiences and perceptions, and to document the prevalence of diabetes. The research team included faculty at the university (Page-Reeves & Mishra), and Graduate Assistants (Niforatos & Gingrich) and individuals associated with ECM (the study coordinator, Regino, and the medical director of ECM's health center, Bulten). ECM has subsequently used our research findings to develop a diabetes prevention initiative that is conceptually framed to account for and leverage local context and culture. The data we report and analyze here are the qualitative component of a larger research study using mixed-methods to investigate dimensions of diabetes in southeast Albuquerque, New Mexico. The qualitative research was led by Page-Reeves.

We collected qualitative data between September and December 2011 through interviews and focus groups. Our broader study also involved a general survey on diabetes-related needs with 100 community residents that included a HbA1c blood test as a surrogate for the prevalence of diabetes (led by Mishra and implemented by Regino) (Mishra et al., 2012) and mapping and geo-coding of census and health data at the local level (led by Gingrich). In addition, our analysis reflects a level of understanding commonly associated with "participant observation" conducted as part of ethnographic research. Page-Reeves has worked extensively in applied settings on a variety of projects with the Hispanic immigrant community and community organizations in the ID since 2006. Although much of this was *applied* work assisting residents to improve health conditions in the community rather than *research*, an anthropological lens informed her activities and interests in the community. In that sense, although the data collection for this article involved focus groups and interviews as discrete moments of data collection, our interpretations and analyses were informed by the type of expansive, multidimensional vision of the community generally understood to emerge

from participant observation. In addition, collaboration with ECM (described in more detail below) as a community partner in the research and participation in the research by members of the Community Advisory Committee (CAC; described below) influenced the way data was collected, analyzed and interpreted. Community engagement in this project provided a dimension of cultural consensus, albeit one that is unstructured relative to models that aim to measure cultural consensus (e.g., Weller, 2007). Combining a public health mixed methods model with anthropologically inspired insights and community participation imparted a level of complexity and detail that we believe offers a way to develop meaningful diabetes prevention strategies.

Roles and Relationships: Researchers and Community Partners

The research for this article is part of a collaborative effort between ECM and its One Hope *Centro de Vida* (Center for Life) Health Center, and researchers at UNM. ECM is a grassroots organization in the ID in southeast Albuquerque with a faith and social justice orientation (http://www.eastcentralministries.org). ECM operates a number of programs and initiatives to assist community members (primarily Hispanic immigrants) with access to health care through One Hope *Centro de Vida* Health Center, and on-site social services, including patient navigation, a food pantry with non-perishable goods and fresh produce, a community garden, and after school tutoring. We were guided by community-driven priorities and used a community-engaged approach in the design, implementation, and dissemination of this research (Montoya & Kent, 2011; Wallerstein & Duran, 2006). The UNM Human Research Protections Office reviewed and approved all aspects of the research protocol, and participants provided signed informed consent prior to taking part in the research study.

In the spring of 2010, as a result of an established relationship between Page-Reeves and ECM, individuals at ECM requested a partnership to develop an initiative to address community concerns that the problem of diabetes is being insufficiently addressed by existing health services and is poorly understood by community members. Because ECM was instrumental in identifying diabetes as a research priority, there was strong community support for and participation in the research from conceptualization to completion. In Spring 2011, Page-Reeves & Mishra collaborated with ECM and community members to develop a grant application for a Community-Engaged Research Project from the Clinical and Translational Science Center (CTSC) at UNM. In March 2011, we received funding to work with ECM and members of the community to gather community input as part of a planning process to collaboratively develop a diabetes prevention intervention. To provide guidance for the planning process, we established a CAC, chaired by the study coordinator (Regino) based at ECM who is a member of the community. The CAC included individuals from the community with diabetes, caregivers of people with diabetes, and a health care professional at One Hope *Centro de Vida* Health Center (Bulten). The CAC actively provided guidance on the overall design of the study, consultation for the development of qualitative and quantitative instruments, input for understanding findings and for conceptualizing next steps, and served as a liaison with the community to disseminate findings.

Study Setting

The International District (ID) in southeast Albuquerque is a neighborhood with many negative social and health indicators, but at the same time, it has unique community assets. In the 1930's, Kirtland Air Force Base was being constructed in the far southeast of Albuquerque. In the area just north of the base, which is today the ID, development occurred

and was driven by the need to create housing for workers building facilities on the Base. Subsequently, urban development in the area accelerated along a transportation corridor that was created in the community with the construction of U.S. Highway 66 (Route 66) that cuts through the middle of the ID as Central Avenue. However, the resulting highway-centered economy declined two decades later when the construction of Interstate 40 diverted non-local traffic out of city neighborhoods. In the ID, contemporary neighborhood dynamics reflect this history.

Today, in comparison to the rest of the county, the census tracts comprising the ID have a low median household income, low mean earnings, a high percentage of persons living under the poverty level, a high percentage of households receiving food stamps, and a low level of education attainment (U.S. Census Bureau, 2010). The ID is densely populated, having one of the greatest densities of multi-unit dwellings in the city (U.S. Census Bureau, 2010). It is also a relatively transient community—among the highest in the county for percent of persons with multiple residences in the last year (U.S. Census Bureau, 2010). In addition, there are several negative diabetes-related health outcomes and risk factors associated with residence in the ID. Parts of the ID have very high rates of diabetes-related and heart disease-related deaths (New Mexico Department of Health, Bureau of Vital Records and Health Statistics, 2012) and high rates of diabetic hospitalizations, and diabetic ambulatory hospitalizations (New Mexico Health Policy Commission, 2009). The potential for an increase in these negative outcomes in the future is suggested by above average Body Mass Index (BMI) rates among children in ID elementary schools (Albuquerque Public Schools, 2009). The general social and economic dislocation experienced by residents is disturbingly expressed in the epithet of "the War Zone" commonly used to describe the neighborhood.

While concentration of low-cost housing in an area with little economic opportunity is associated with many negative social dynamics, the abundance of inexpensive housing units has made the ID a destination for immigrants over the previous four decades, creating one of the most culturally and ethnically diverse neighborhoods in the state (Childress, 2009). In the 1970's, thousands of Vietnamese immigrants moved to Albuquerque through the State of New Mexico Indochina Refugee Resettlement Program, mostly settling in the neighborhood that is today the ID (City of Albuquerque, n.d.). Since then, many families have settled in the area from other Asian countries, Africa, and more recently from Latin America. Today census data for tracts comprising the ID indicate that the area has among the highest rates of foreign-born residents in the County (U.S. Census Bureau, 2010). The ID has a very high percentage of Hispanic residents and a very high rate of Spanish speakers who indicated that they speak English "not very well" (U.S. Census Bureau 2010). In the last few years, community-driven efforts have sought to draw positive energy from this cultural and ethnic diversity, culminating in the recent declaration of the area as the city's official 'International District.' The health and social justice work of ECM is situated as part of this process of community revitalization.

Data Collection

To gather the data discussed here, we conducted three focus groups in Spanish involving a total of 18 people, and key community member interviews in English with six individuals. Our method for selecting participants was "purposive" and dynamic (Ellingson, 2011). Regino, the Study Coordinator, recruited focus group participants using a snowball approach through the ECM's social networks. The CAC, the ECM executive director, and the medical director of One Hope *Centro de Vida* Health Center (Bulten) identified "key community members" to participate in interviews and they were recruited by the study

coordinator. Regino (a trained and experienced focus group moderator whose first language is Spanish) led the focus groups, assisted by Page-Reeves (an English/Spanish bi-lingual anthropologist). Each focus group was held in two sessions. In the first session, we explored factors impacting diabetes prevention and control; in the second session, we obtained input on strategies for, and the design, content and implementation of interventions to address the burden of diabetes in the community. We used a semi structured question format to allow us to use follow-up inquiry and probes to pursue discussion threads relevant to the research. Niforatos, who is trained in anthropological methods, conducted the six interviews in English with key community members who are bilingual Spanish/English speakers. The interview question format was also semi-structured. Niforatos used follow-up inquiry and prompts to encourage the participant to direct the flow of the conversation with respect to each question. We based the interview questions on the same key areas that guided the development of the focus group questions. The CAC convened periodically to assist in (a) designing the line of inquiry and the questions that would be asked, (b) to review and discuss preliminary data and the data collection process, and (c) to provide input into interpretations of the data. This process provided a voice for community members in the research, strengthened the validity of the analysis, and helped to reduce individual researcher bias.

Data Analysis

We conducted a rigorous, disciplined, empirical analysis of all data following Hammersley's (2008) criteria based on plausibility, credibility and relevance. We used a synthesis of interpretive methods (Creswell, 2011; Creswell, Klassen, Plano Clark, & Smith, 2011) leveraging insights from ethnography (Krumeich et al., 2001; Lambert & McKevitt, 2002; Madden, 2010) and social theory (Dressler, 2001; Giddens, 1984; Winkler & Degele, 2011) to develop a theoretical understanding of our findings. We analyzed the data from focus groups and interviews inductively as one data set using latent structural content analysis with modified grounded theory-based coding (Charmaz, 2011). Page-Reeves and Niforatos reviewed and coded the data. Through consecutive review (2x) of data prior to coding, we identified analytic domains and patterns grounded in the data for understanding people's experience and perception of factors that might affect their risk for diabetes, and for thinking about what can be done to prevent it. Following review and discussion of preliminary analysis with the research team, the study coordinator and a member of the CAC, Page-Reeves and Niforatos identified and coded systematic themes and sub-themes within the domains. To explain patterns within each theme or sub-theme, we analyzed coded data for coherence and developed interpretations. Analysis developed through this process was again further expanded by group discussion with the larger research team. Page-Reeves and Niforatos presented preliminary interpretation of the data to the CAC for discussion and input to deepen and refine the analysis. Final interpretation of the data reflects and incorporates CAC input and ideas.

Dissemination of Results

Final results from the research were presented by members of the research team including the Regino in individual presentations at a panel we organized for the joint annual conference of the New Mexico Public Health Association and the NM Cares Health Disparities Research Center at UNM. Page-Reeves, Regino, Gingrich, and Niforatos presented findings at a meeting of the International District Healthy Communities Coalition. Findings from all components of the research were developed into a community report (Mishra et al., 2012) that was disseminated locally to assist members of the community with

understanding the issue of diabetes and to support their efforts to find funding and develop interventions.

Results

Thematic Domains

Our analysis revealed opinions or experiences related to two domains. Within the first domain (contextual factors affecting people's ability to live a healthy lifestyle) six themes emerged: (a) Money and expense; (b) Stress and fear; (c) Being physically active is challenging; (d) People eat unhealthy food; (e) Food as social practice; and, (f) People lack information. Within the second domain, people expressed a variety of opinions about and ideas for diabetes prevention. The multi-dimensionality of these data demonstrates the importance of understanding the political economic and cultural context of health behaviors and outcomes (Clark et al., 2009; Lambert & McKevilt, 2002).

Domain #1

(1) Money and expense

Money is a significant factor for people when thinking about healthy lifestyles and diabetes. Most obviously, people discussed the cost of drugs, doctors and treatment for diabetes care and for prevention. Participants indicated that access to health care is difficult if you do not have sufficient financial resources. One participant said, "Because of a lack of money, we can't go to the doctor." Participants reflected on the actual expense involved, which was considered to be high, with comments like, "They admitted me in Emergency and then they charge you for all of that!" and, "They charge you for everything that they give you plus the doctor!" However, most commentary about money actually focused on what happens when you cannot pay. One participant explained how expenses increase because of interest on unpaid balances, saying, "There are companies that do the collection. If you don't pay, the interest keeps rising." More ominously, another said, "They charged me $40 plus $100 in Emergency and they just keep sending me bills, and now I am just ignoring them." Participants identified language as a barrier to understanding health care expenses and being aware of costs. Printed bills or other materials that come in the mail are often in English and many people who are monolingual Spanish speakers do not have a way to translate them. One participant said, "If you don't pay, they will send it to collection. But we don't know because they send it in English."

In addition to the high cost of health care, participants also believe that buying food that is "healthy is more expensive," or at least, it "seems more expensive." They perceive whole grain products, fruits and vegetables to cost more than other, less healthy food. One participant said, "I think there is a barrier in terms of money. It is more expensive. A family, when there isn't enough money, will they buy the whole wheat bread that costs more or the white which is cheaper?" Another said, "Our income doesn't allow us to buy healthy food. We have to be able to buy more, enough to allow the family to eat." Participants also identified what they see as unequal access to healthy food in their neighborhood as a result of few places that sell high quality, affordable fresh produce within walking distance, and an overabundance of fast food restaurants and quickie marts in the neighborhood as compared with other areas of the city.

(2) Stress and fear

Participants discussed how stress influences behavior and health in the community. They indicated that life in the United States is more stressful than in Mexico, in part because people have to worry about covering many expenses. One participant described how stress affects the lives of people and the entire community saying, stress "is a problem in the community. The clinics are closing or the clinics are full. The people, they all have stress and income is low. This falls over the whole family and over the community. It is a circle." Others discussed how fear is a pervasive dynamic for people in the community. Fear was identified as multidimensional. People are afraid of the potential cost involved with going to the doctor. One participant discussed the extent to which "people are afraid to go to the doctor. They can't afford the bills, can't make the payment. They are scared, afraid." Another said, "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 there's the same fear that they will see me and check me and I will have this big bill, thousands of dollars." The fear of financial trouble is exacerbated by the fact that many of the people in the neighborhood are "undocumented." This means that their lives are enveloped in a fear of being discovered. Participants in this study discussed how this fear is connected with people's fear of high medical bills that they might not be able to pay, saying that they "run on fear because of their documentation status. If a bill collector is bugging them, then they fear INS [U.S. Immigration and Naturalization Service] may be looking over the bill collector's or the [hopsital's] shoulder. People are really fearful."

Our data indicate that many people in the neighborhood use "alternative" remedies, traditional healers and herbs. They use these things because they are looking for a way to treat or control their diabetes, because a friend or family member might have suggested it, and because it is often less expensive than prescription drugs and doctor visits. The use of these remedies makes some people fearful of what their doctor will say and they are afraid to mention that they use them. 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."

For many, the diagnosis of diabetes itself causes fear. One participant described the way that people feel when they were told they are diabetic as "just being afraid. They hear the word diabetes, and they think they're dying tomorrow." This multi-dimensionality of fear in the community means that the pervasive fear under which people are living makes the possibility of illness that much more frightening. One participant explained what this means for people, saying,

> For poor people in general, they become fatalistic and just say, "this is so complicated, life is so tough anyway," and for people in our community life is tough, and they are living on the edge financially, and there's this fear factor and so on. Life is tough, and now you dump something else on them, like monitoring blood sugar.

(for a more detailed discussion of fear in this context using a structural violence framework, see Page-Reeves et al., 2013)

(3) Being physically active is challenging

The participants recognized that there is a relationship between the neighborhood environment and health. They believe that in Mexico it is still common for people to live in

places where walking is a part of everyday life, but that in Albuquerque that is not the case. They discussed how in the United States, "it is not the custom to go by foot; everyone goes by car." People laughed about the fact that they tend to try to get the closest parking space when they go to the store so that they will not have to walk a few more steps, or that there are now motorized carts that allow people to ride through Walmart or through the grocery store. They associate these dynamics with a lack of physical activity in their own lives.

Others discussed built environment barriers to being physically active. Badly maintained or poorly designed physical space makes it difficult for people to walk or ride bikes or skateboards. Participants said, sidewalks and roads in the neighborhood are "horrible, whoever designed the city must have had rocks in their heads," and that it is a "physical hazard to walk on the sidewalks in this community." Another said the sidewalks and roads are "awful. They're cracked, they're bumped, they're badly designed. Going running will break your back here."

Although participants expressed concerns about the built environment, they identified neighborhood safety as a greater barrier. Participants indicated that even where the built environment or cultural norms for physical activity are not ideal, people would be able to be more active, if it were not for dangerous conditions in the neighborhood. One participant said, "if people aren't physically active in this community, it's because they don't feel safe. Homeless folks, inebriated folks, people doing drugs, prostitution, it's much more visible here than in other communities." Participants described safety concerns for their children. One participant said, "If I let him out, he finds syringes and condoms. He can't play outside." Another detailed an experience with a "flasher" exposing himself to a group of girls. Others described why it is not safe for anyone to be out, saying, "On my corner, they cut someone's throat," or "Look at this area, they call it the *War Zone*."

Beyond neighborhood barriers, participants acknowledged that being physically active in today's society is challenging in terms of cultural norms that favor driving, and limited time because of work, family schedules and obligations. One participant said, "You just have to force yourself." Others discussed how for people who have diabetes, being physically active is even more challenging because they feel that they "have no energy." Still others believe that many of the people in the community actually are physically active in ways that are not considered "exercise" because they engage in activity through their jobs in construction, restaurants, or cleaning/sanitation.

(4) People eat food that is not healthy

Participants identified the type of food that is commonly eaten by people in the community as contributing to poor health. They expressed strong opinions about the poor quality of the food available in stores because of unhealthy additives and processing, or high levels of fats and sugars. This food was described as "*comida desechable*" [disposable food] or "*la comida chatarra*" [food that is crap]. These foods were contrasted with traditional Mexican foods and cooking techniques that are seen to be more "natural." At the same time, participants tended to believe that "healthy food" does not taste as good. One participant said, "When you look at the side of the menu that is *healthy*, it doesn't look appealing."

Participants also recognized that "traditional" Hispanic cuisine often contains ingredients or requires preparation techniques that do not contribute to a healthy diet, especially when eaten in quantity or on a regular basis. In particular, participants identified the use of lard and the greasiness of many foods, the tendency for people to eat large amounts of carbohydrates at each meal, and the attitude that a heaping plateful of food is considered a *normal* serving size, as contributing to the unhealthy quality of traditional eating habits. Although participants acknowledged that traditional cuisine can be a liability, some of the

most animated discussion within each of the groups occurred when participants described the flavors and components of traditional foods. Participants spoke lovingly and with desire in their voices, describing long lists of dishes that they relish eating. The variety of dishes and the depth in which they were described by participants in the space of a short discussion was actually rather impressive. Because these descriptions were provided in the context of a discussion of diabetes and health, the tone was often apologetic or coy, with people acknowledging that these are foods that they believe that they should not eat, but that they cannot imagine giving them up, regardless of whether they are healthy choices. There was a definite sense that in many cases, it is preferable to eat the food and suffer the health consequences rather than have to give up a beloved dish. One participant who cares for a family member with diabetes said that "he says, if I am going to die, I will die, but it is better to die full." Another participant explained this as, "It is the custom, the style of life." Others framed it as food in Hispanic culture is "*lo principal*" [the principal thing], and that "I think that the food for us Mexicans, the food is part of our identity." In thinking about an intervention to promote healthy eating to prevent diabetes, one participant criticized descriptions of traditional food as unhealthy, saying, "Calling a whole group's cultural food unhealthy creates a huge barrier." He described some of the larger issues of power involved in his experience working with projects or organizations that

> insist on serving salads and things which are outside of people's normal experiences, being that they are the funders, there's a power issue. We're here and we disrespect your food. When you do that, you disrespect their culture. When I get forced upon, and they want me to be healthy, it's patronizing, insulting.

(5) Eating as social practice

Data from this study demonstrated the social dynamics involved in the nexus of food and cultural identity. Participants discussed how women family members (e.g., mothers, grandmothers) "*exijan*" [insist] that others eat the food that they prepare, and that not eating is taken as a personal affront by the cook, or that it is common for the person serving the food to say, "*cometelo, no te pasa nada.*" [go ahead, eat it, it won't hurt you]. Participants said, "My mother was always cooking and it was important to her that we eat. She felt it as a rejection if we didn't," and, "we are like that. We go to people's places and they offer food. We don't want to say no because the woman will feel bad and in order not to offend her, you don't say anything, you can't say anything negative." Participants described the logic of what happens when someone tries to avoid saying "no" which would risk offending the cook, in that "instead of saying 'no,' people say, 'OK, just a little.'" Participants recognized that many people are struggling to adopt or maintain healthy eating habits, and that this dynamic "affects us negatively. They make us eat more."

Throughout the data, the focus of this commentary remained on the social nature of the act of eating the food. Participants indicated that they eat the food to address the needs of others (for acceptance, for feeling loved, for feeling needed, for feeling appreciated) and that "you sacrifice for them." At the same time, the social nature of the sacrifices that people make around food and eating also had another side that people believed to have a positive influence on health. While they saw it as very difficult for the person making the change to confront social norms and values related to food, eating, and receiving food prepared by others, participants also placed a high value on family members who make lifestyle or personal changes to support other family members required to make a change because of a health problem like diabetes, high blood pressure or cancer. The act of change on the part of

family members was construed as "solidarity" with the person who is ill. Participants described examples, such as, "when my uncle had a heart attack, so the whole family changed in order to be in solidarity," "When my uncle had cancer, we had a family meeting to support him. All the men cut their hair in solidarity," and, "Our culture, it is very closed. In my case, we all had to learn to eat in solidarity with him. It was the *negation* of our culture." Another participant said, "We all became vegetarians when my uncle had to eat that. We had to help. I lived that in my family *como un apapacho* [like a doting upon the person or to spoil him]." The idea that in cases involving the family, "we all have to *apapachar* [participate in the doting/spoiling]" was commonly agreed upon by the groups. This type of social solidarity that acts to negate the cultural centrality of food was seen by participants to be particularly strong within Hispanic families, as compared with Anglos. "I think there is more support in Hispanic families….*solidaron* [they act in solidarity]." Although participants recognized that the strength of this bond is different from family to family, they felt that it was important for families to change together and they described how some develop "action plans" to deal with the health needs of family members that require the entire family to make changes. One participant believed that Hispanic culture can be a positive influence for people trying to adopt healthy lifestyles because "we try to change the way to eat or to change our habits and it is especially strong when it is inside the family."

(6) People lack information.

One of the most common and straightforward themes to emerge from the data for this study was that participants believe that they do not have sufficient information to: (a) know where to purchase healthy, affordable food; (b) know which foods to purchase; (c) know how to prepare healthy meals, especially with respect to culturally appropriate foods; (d) know where they can participate in organized physical activity; and (e) really understand the symptoms of diabetes and the relationship between diet and diabetes. Participants said things like, "*Nos falta mucha informacion* [we really lack a lot of information]," "We don't have information," and, "*No hay informacion* [there isn't any information]." And even more concretely, "That is what I want: information. I want precise information."

Domain #2: Strategies for Diabetes Prevention

When asked what could be done in the neighborhood to prevent diabetes, one of the first things that was mentioned was the idea of having a health fair to provide people with information and possibly have opportunities for free screenings. A number of participants suggested a larger campaign "to inform everyone" with pamphlets would be beneficial. However, there was some sense that these approaches have been tried and are not effective, and that diabetes prevention requires different tactics. One participant said, "pamphlets are a waste of money, and they won't even be able to use it as toilet paper. They try to squish so much information into it, and they don't even make sense. They only work when there's one-on-one information."

The bulk of the discussion about diabetes prevention then focused on strategies for providing people with support in a variety of ways. A principal theme was the idea that social support motivates people and makes it easier for them to make lifestyle changes. Participants said, "A group of support can change the quality of life through acceptance. They can do things together"; it would give "people motivation. If you have *flojera* [laziness] then the group helps"; "*Solitas* [alone], they get scared or sad or bored"; and, "The important thing is to share the experience." In particular, there was a great deal of enthusiasm for the idea of having a variety of culturally situated classes or groups dealing with different themes, but that

"it has to be based on their tastes and values." Examples discussed included: (a) Nutrition and cooking workshops, including how and where to shop for healthy food, how to read labels, and how to adapt traditional recipes to be part of a healthy diet; (b) Exercise classes, with dance and *zumba* being mentioned as especially attractive in Hispanic culture; and (c) Walking groups. Participants described how these events and groups could be a "*conviviencia sana*" [a healthy group experience] to engage families in the process. One participant said, "if their family gets very supportive, it makes it easier. Families here tend to be pretty close-knit. If your family is on board, that's great. If they're resistant, then you're going uphill."

Having "*citas compartidas*" [shared/group appointments] was one suggestion for group support. Most participants thought that having a group appointment facilitated by a provider for education and sharing, together with individual consultation about sugar levels and other personal health issues, would be effective. Participants said, "Everyone would share, like this focus group. One doctor, they would meet in group and then get checked individually," "Each one would feel supported but they would also share individual experiences because not everyone will have the same experience," and, "It should be done in groups; one-on-one when necessary for your specific condition. It takes pressure off providing the program. When there are groups, if one person can't make it others can take over to keep it self-propelled." A *promotora* [community health worker] model was also suggested as a way to "raise consciousness [about diabetes and health] in the community." Participants believe that a promotora-based model would "really work in this community."

Discussion

The findings from this research demonstrate that a variety of contextual factors make it difficult for people to live a healthy lifestyle. Factors related to low socio-economic status (SES) make it difficult for people to afford health services, buy healthy food and find the time or a safe and appropriate space to be physically active. Neighborhood conditions associated with low SES contribute to this dynamic through the poor quality of the food environment (low quality food and a high number of fast food /quick mart establishments), poor quality and design, and lack of maintenance of the built environment (sidewalks), and the lack of public safety (pedestrian safety and crime). Immigration status issues present a challenge manifest as a pervasive fear that makes it difficult for people to believe that they can seek services and support. Cultural factors also significantly influence the way that people in the community experience the food environment (i.e., food offered at a social event, food preferences and eating habits, and importance/centrality of food in Hispanic culture) and how they perceive the health-related needs of others.

Limitations of this Study

This study was limited by the fact that project funds did not provide sufficient support to allow for more detailed analysis of the data based on differences between participants such as those who have diabetes, those who do not have diabetes and those that are caregivers for people with diabetes. Our findings would also be expanded if we could attribute quotes to individuals based on gender, age or level of education. Because in recording discussions during focus group sessions, we were only able to capture what was said and not who said it, it is not possible to include this information in the presentation of the analysis. However, members of all three groups are represented in the research. Despite these limitations, we believe that our findings provide valuable insights.

Implications for Research Approach

These findings contribute to a nuanced understanding of local diabetes-related needs, experiences, and perceptions in a Hispanic, immigrant community in Albuquerque. We developed this understanding using an anthropological lens to understand the lived experience of diabetes combined with a process of working collaboratively with community members. Following guidance from recent literature, through our approach we responded to community-determined priorities and engaged community members in developing ideas for solutions. Our community partners at ECM subsequently used findings from this study to inform the planning of a prevention program to reflect the local context and culture (Trickett, 2009). In addition to insights that result from analysis of the data gathered that relate specifically to diabetes and diabetes prevention, research presented here also illustrates nuances in the process of co-developing and co-creating a prevention intervention with members of a community. The experience outlined in this article begins to tell a "story" (Trickett, 2009) that helps us to conceptualize a community-engaged research continuum with the potential to create interventions that will have increased effectiveness and broader impact.

Implications for Theory

The richness of the data reported here also reinforces the importance of context for understanding health, yet not the one-dimensional conceptualization of context often associated with a socio-ecological model that acknowledges that individuals exist within a context of social determinants without investigating how those social determinants operate. We propose that these data underscore the need to conceptualize social determinants more broadly, more affectively and more dynamically than often considered. Participants in this study indicated that health care costs and neighborhood safety are just as critical to understanding how to prevent diabetes as changing people's individually and culturally based dietary and physical activity habits. These results highlight a need to include, in addition to individual-level factors that are traditionally the focus of public health (e.g., individual behavior and choices, self-image, self-efficacy, and readiness for change) and more innovative structural factors that are currently in vogue (e.g., built environment and policy), an in-depth, qualitative exploration of local context, social environment, and culture, and their interactions and intersectionality, as key factors when considering how to achieve change (Burkner, 2012; Schulz & Mullings, 2005; Trickett, 2009; Viruell-Fuentes et al., 2012; Williams & Sternthal, 2010). How else are we to make sense of the data presented that indicate multidimensionality of people's behavior and the relationship of factors that are not often considered within the health paradigm as related to people's ability to adopt a healthier lifestyle?

The abstract complexity of these data also requires us to have an understanding of the interconnected, dialectical and recursive relationship between individual agency, structure and social practice (Dressler, 2001; Frolich & Potvin, 2010). Dressler (2001) suggests that a unique strength of anthropology is the ability to understand that "meaning resides in collective representations that cannot be entirely reduced to individual perception" (p. 458). The key is not in contrasting opposing dynamics construed as individual agency *versus* the contingencies of structural forces, but in the "intersection of social structure and cultural construction" (p. 462). Our findings dovetail with work by Mulvaney-Dey and Womack (2009) that encourages understanding of these factors as multidimensional and associated with key "identity-constitutive affiliations" (p. 252) that often define individual behavior. They propose that if we can understand these dynamics, it is possible to frame the

development of prevention initiatives to leverage cultural identity, social relationships and the agency of individuals for more positive outcomes. Our data suggest that a focus on cultural assets based in social solidarity and family (while acknowledging limitations presented by the existing political, economic and cultural context) could strengthen any attempt to promote healthy lifestyles and diabetes prevention in the ID. This is the approach now being pursued in a diabetes prevention initiative by our partners at ECM.

Conceptualizing Community Interventions

We believe that the information presented here supports an emerging paradigm that:

1. acknowledges the value of anthropological methods and perspectives for understanding the complex and dynamic nature of interventions in communities;

2. incorporates an ecological approach in community interventions in a way that builds capacity in the community;

3. embraces the importance of collaboration; and

4. recognizes the cross-cutting relevance of culture. We conducted this research in a way that contributed a multi-dimensional perspective on the diabetes-related health challenges faced by the Hispanic immigrant community in southeast Albuquerque.

As Smith Morris et al. (2012) eloquently phrased it, anthropology gives us the tools to consider "the instructive power of less visible or less quantifiable details from such smaller, yet still instructive samples" (p. 3). Our approach also allowed community members (the CAC) and researchers to co-create an environment that fostered engagement and inclusion in a positive way, and developed critical health literacy in the community (Griffith et al., 2008; Wallerstein, Yen, & Syme, 2011). Empowered, critically health literate community members have an increased potential to make positive changes in their community.

Implications for Intervention Design

The anthropologically inspired, co-creational process we followed has allowed ECM to develop and implement a more meaningful and realistic diabetes prevention initiative that is applicable to a *real world* setting by being responsive to community needs, acknowledging limitations of the local built environment and socio-economic realities, contributing to critical health literacy, and using an assets-based approach that identifies community and cultural strengths rather than emphasizing deficits and weaknesses. Following Trickett et al. (2011), rather than "tailoring" (p. 1412) an intervention to the culture, we see culture as a nexus for identifying cultural constructs, symbolic meanings, and "identity-constitutive" affiliations (Mulvaney-Dey & Womack, 2009, p. 252) that can be used to frame evidence-based strategies to diabetes prevention in the community. Based on input from the CAC, the positive cultural dynamics related to social solidarity and family that we identified above have been leveraged by ECM in the employ of diabetes prevention with a high-risk, urban, Hispanic population. Cultural ideals related to the importance of sacrificing for others (framed as *solidarity*) and the value placed on the role that family members can play in supporting lifestyle changes required for health reasons (framed as *apapachando*) are now

being translated into a framework for community diabetes prevention. Such activation of positive cultural values to promote community health also has the potential to, as Mulvaney-Dey and Womack (2009) suggest, create new cultural norms and new identities from which people can derive strength and around which they can mobilize.

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