

*Women and Health* 43(4), 2006

**Using Participatory Research to Build an Effective Type 2 Diabetes Intervention:  
The Process of Advocacy Among Female Hispanic Farmworkers and their Families In Southeast  
Idaho**

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**ABSTRACT**

The *Formando Nuestro Futuro*/Shaping our Future project (herewith, *Formando*) is a community-based participative research (CBPR) focused on type 2 diabetes. It was conceptualized and designed by a team of university-based researchers and community health workers (promotores). This article describes the process of establishing a CBPR project such as *Formando* and the most current results from that project. The *Formando* project is an example of health-focused advocacy with the Mexican agricultural workers in Southeast (SE) Idaho. To date, 172 qualitative interviews on participants' knowledge about type 2 diabetes have been carried out with farmworker women and their families. Biometric data (heights, weights, blood pressures and fasting blood glucoses) were obtained from participants. Fieldnotes, focus group discussions and key informants were used to triangulate findings. Significant quantitative findings include that age was significantly associated with Body Mass Index (BMI) ( $p < 0.001$ , Spearman Correlation  $< 0.001$ ) and with elevated fasting blood glucose ( $p < 0.001$ , Spearman Correlation  $< 0.001$ ). The qualitative interviews were thematically analyzed. Key themes associated with type 2 diabetes in this community were the connection between thinness and vanity, dieting and starvation and the onset of diabetes as a result of, what social scientists call, structural violence within the immigrants' daily lives. We conclude that long-term commitment to using the CBPR approach in these Mexican agricultural communities is an effective way to engage in health research and to establish real and meaningful dialogue with community members.

Key words: community-based participatory research (CBPR), advocacy, Hispanic farmworkers, type 2 diabetes, community health workers (CHWs).

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**Introduction**

Human rights violations are not accidents; they are not random in distribution or effect. Rights violations are, rather, symptoms of deeper pathologies of power and are linked intimately to the social conditions that so often determine who will suffer abuse and who will be shielded from harm (Farmer 2003, p. 7).

In this article we first describe the long-term process of establishing our community-based health research projects with the Mexican agricultural worker<sup>1</sup> communities in Southeast (SE) Idaho. The research and advocacy work was done through the Hispanic Health Projects<sup>2</sup> (HHP)—a group of

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<sup>1</sup> The majority of the agricultural workers who are involved in our projects call themselves “Mexicans” although some also use “Hispanic” to describe themselves. The terms are used interchangeably here. Most of the individuals who have contact with the HHP have come to the U.S. in the last 10 years or so from Mexico to work in the potato, wheat and sugar beet fields of SE Idaho. Many also work in the potato processing factories for part of the year.

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individuals dedicated to improving the health of Hispanic agricultural workers through promoting social justice at the individual, community and national levels. We then describe, in detail, the results from our first year of an on-going research and intervention program focused on type 2 diabetes.

Working from the notion that health is a human right, the HHP's research projects attend to issues of documenting and assessing Hispanic farmworker families' access to appropriate treatments and to preventive health care. The HHP team also engages in research that precisely describes individual understandings of diseases and their treatments as well as gathering biometric data that describe the burden of the disease on this particular community. Subsequently, the knowledge generated through the research projects is used to create consciousness raising and dialogue about health and social issues that are most important to the community members

The HHP is conceptualized as a three-pronged approach to understanding and changing the health of the underserved, Hispanic farmworker communities in the U.S. through research<sup>3</sup> (that identifies and explores health problems and raises consciousness of the issues within the community), education (of community members and the larger society), and interventions (based on the results of the research projects). Recognition of the large amount of time that it actually takes to facilitate a change in the health status of a group of individuals within a community is essential in work such as this. The HHP research and intervention programs are set up to keep working toward collective health goals until they are reached, however long that takes, and whether the goal is decreasing the prevalence of type 2 diabetes, or the rates of untreated cervical cancer, HIV/AIDS transmission, the number of pesticide poisonings, or domestic violence incidents. Real change takes time.

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Rural Employment Opportunities of Montana, and the AVON breast cancer crusade. The contents are the sole responsibility of the authors and do not necessarily represent the official views of the funding agencies.

<sup>3</sup> All research projects were reviewed and approved by the Human Subjects Committee, Idaho State University. Informed consents were written in both Spanish and English and were signed by all participants.

Oftentimes, researchers who work on health issues with Mexican agricultural workers avoid discussing and researching the parts of the bi-national realities of Mexican immigrants that relate to the contemporary immigrant experience for Mexicans who come to the U.S. to work in agriculture and other entry-level jobs. Instead, research projects focus on particular “health” problems, such as a particular disease, without contextualizing the experience of that disease within the context of what it is like to live in the U.S. as recent, often undocumented, immigrants. The realities of immigration are embedded within commonly used clinical and research vocabulary such as limited access to care, stages of acculturation, and women who arrive at the clinic for late prenatal care. Late prenatal care is as much about not getting in for a sonogram and a supply of prenatal vitamins as it is about the terror of being discovered as “illegal” when applying for services at the clinic and subsequently being deported for immigration violations. It is also about the realities of navigating the U.S. legal system, the endless hours of work needed to amass the money to make another crossing attempt of the U.S./Mexico Border, the corrupt officials in both countries and the physical and psychological dangers of crossing through that ever-more-militarized zone that divides the United States and Mexico (Heyman 1995).

The HHP’s research is aimed at understanding how illnesses are experienced within particular social and cultural contexts. While many cultural differences exist in how illnesses are discussed and in what home treatments are used, the social and political realities of the immigrant situation often take precedence in both individual conceptualizations of why health problems occur as well as in, ultimately, if an individual receives treatment. The difficulties and indignities present in living as a recent immigrant in the U.S. consistently appeared in thematic analyses in our health research projects and ultimately, served as highly generative themes of discussion that facilitated a translation of our research into community action targeted at ameliorating such things as access to health care, medical interpreters and other needed resources.

Women in these farmworker families are the primary care givers within the family unit. They make the decisions about preventive strategies, family nutrition, home-based/traditional treatments for

illnesses, as well as about when to use biomedical care and how and if to follow the subsequent biomedical treatment regimen. For example, in the realities of living with type 2 diabetes, the women are pivotal both in caring for their own diabetes problems, as well as for those of their spouses, older relatives and more and more often, their children. While the HHP's approach is always family-based, it is the women who are the main focus of our research and education programs.

This paper highlights the process of engaging in long-term, sustainable health research with Hispanic farmworker women and their families. We first briefly describe three research projects that have been undertaken, one after another, during the last seven years at the HHP that were designed to research health care issues and needs of the Hispanic women and their families. The inter-personal work of gaining access to families and in establishing a trustful working relationship with them is an integral part of CBPR (Brown & Vega 1996). Each research project and health education intervention is seen as another step in the process of establishing a fruitful working relationship between the academics and community members of the HHP, the Hispanic farmworker families in the region and the local health care professionals. We conclude with a discussion of insights from the *Formando* Project in the context of this process and how they can further refine our understanding of the cultural and social particulars inherent in implementing CBPR projects that are intended to raise the level of awareness about a health problem and to begin the process of helping individuals to lead healthier lives.

## **Background**

### ***Hispanic Farmworkers in the United States: Hidden Populations, Hidden Health Problems.***

Immigration and health are inextricably intertwined in individuals coming from Mexico to work in the U.S. Until the 1930s, the U.S. did not have an immigration policy with respect to Mexico. The Bracero Accord was initiated in 1942, and during the twenty-two years of its existence this program allowed over 4.6 million temporary workers to enter the U.S. (Durand, Massey & Parrado 1999, p. 519). Between the end of the Bracero Accord in 1964 and the Reagan administration's Immigration Reform and Control Act

(IRCA) of 1986, millions of documented and undocumented workers moved between the U.S. and Mexico.

The IRCA of 1986 contained new funding for two different components of immigration control. On the one hand, it included funding to hire more Border Patrol agents and increase Border infrastructure as well as increasing sanctions for U.S. employers who hired undocumented workers. Interestingly, the same bill also contained the amnesty/legalization programs the Legally Authorized Worker Program and the Special Agricultural Worker Program (Durand, Massey & Parrado 1999, p. 521). One of the goals of the IRCA was to generate a “clean slate” by legalizing those undocumented workers who could prove they had continuously been in the U.S. living and working since before January 1, 1982 (Public Law 99-603). Approximately, 2.3 million workers took advantage of these legalization programs and became permanent residents of the U.S.

In many cases, those who qualified were men who then sent for their wives and children back in Mexico to come join them in the U.S. Women and children subsequently arrived, many without legal immigration status. The net result was a vast increase in undocumented Mexicans coming to live permanently in the U.S (Durand, Massey & Parrado 1999, p. 525). Since the IRCA was passed in 1986, these new immigrant families have tended to move into rural areas, such as SE Idaho where the HHP is located (Durand, Massey & Parrado 1999, p. 530). While the HHP never asks individuals for their immigration status, proxy data on payment methods at clinics, show that over 50% of the Hispanic farmworkers in the area are probably undocumented.

According to the 2000 U.S. Census, the population of the state of Idaho is 1,293,953, of which 101,690 individuals self-identify as Hispanic or Latino (7.9%; U.S. Census Bureau Statistics 2000). In the southern half of Idaho, where the majority of Idaho’s agriculture takes place, Hispanics are a much larger percentage of the overall population. This is the case in the two study sites of American Falls and Aberdeen. In the last ten years, the percentage of Hispanics in these two small Idaho towns has nearly

doubled to between 30-40%. Hispanics are playing an increasingly vital role in the social and cultural life in Idaho's small, strongly religious, and conservative farming communities.

Hispanic farmworkers in the U.S. are at risk for many conditions of ill health. According to Villarejo & Baron (1999) these conditions can include poor nutrition, anemia, tuberculosis, parasitic infections, communicable diseases, diabetes, cancer, hypertension, high-risk pregnancy, respiratory problems resulting from exposure to dust, fungus, and pesticides, dehydration, heat stroke, urinary tract infections, and depression. Farmworkers in SE Idaho also experience these problems. According to the HHP's 1998-1999 community needs assessment, Hispanic agricultural workers in SE Idaho have an average annual family income of \$10,000 and an average family size of five individuals, 75% have no insurance, and over 88% speak only or mostly Spanish (Hunter, Hall, Hearn, & Cartwright 2003; Early 2001; Guzzle 2000).

***The Process Of Community-Based Diabetes Research With Hispanic Farmworkers In SE Idaho.*** The HHPs have evolved over the last seven years through a process of completing several CBPR projects and health education interventions. First, a community health needs assessment survey was performed in 1998-1999. The goal of the survey was to detail overall health concerns in a general manner. The survey, based on Slesinger's (1992) similar work in the Midwest, was administered to 179 adult, Hispanic farmworkers who were currently working in either the fields or the potato processing plants. The participants were chosen from a convenience sample with a participation rate of greater than 99%. The research assistants who implemented the survey had worked or were currently doing farm labor in the study communities. The team was also composed of some bi-lingual university students. The interviewers were all trained in survey research (see Hunter, Hall, Hearn, & Cartwright 2003 for a full description of the quantitative analysis of the survey).

To clarify some of the quantitative survey results, three members of the HHP engaged in a series of in-depth qualitative interviews with forty Spanish-speaking adults (Early 2001; Guzzle 2000). The

interviewees often made comparisons between the medical care in the U.S. and Mexico that allowed the research team to understand the context within which the farmworkers were judging the care that they received in Idaho. One of the interviewees made the following observation:

In Mexico if a person cannot pay, they don't receive treatment, the doctors just tell them, "There's nothing we can do". And like my brother-in-law, he cut his hand off (doing agricultural work in Idaho). Here, in the U.S., they re-attached it. It didn't matter if he could pay or not. If that would have happened in Mexico, if you can't pay for the operation, you cut your hand off and that's it. So, (in Mexico) you don't have to pay the hospital bill, but you don't have your hand. Now I understand why we came here. (Guzzle 2000, p. 92)

In the case of life-threatening, emergency situations, farmworkers in SE Idaho do have access to care far beyond what many could expect in rural Mexico. Paying the astronomical hospital bills, after the fact, is a constant source of stress for the majority of the farmworker families in our study—but most are glad to have received the emergency medical care.

The perception of discrimination against Mexicans, both those recently immigrated as well as those born in the U.S., is an over-riding theme that has emerged regardless of the health topic under discussion. Disenfranchisement with respect to the larger, Anglo society is reinforced through serious language barriers as well as through fear and misunderstandings that abound in the small, rural, agricultural communities of SE Idaho. Basic issues of miscommunication and misunderstanding need to be considered when interpreting both survey and interview data.

Diabetes research provides a clear example of how long it takes individuals to open up about their feelings and perceptions about a serious disease. The 1998-1999 community needs assessment survey showed that diabetes was listed as a problem for only about 5% of the survey respondents and their families. This number seemed very low to those members of the research team who had experience working with this community. The reasons for this kind of under-reporting were not obvious until we had

learned how to communicate more effectively about this health issue. The team agreed that surveys were of limited value in this Spanish-speaking community where immigration-related problems abound, and distrust of outsiders is quite pronounced. Following-up on the issue of diabetes, researchers at HHP engaged in clinical chart reviews of 100% of the diabetic patients seen at the local community health centers (Hunter, Cartwright, & Hall 2001). These chart reviews showed that individuals were not being diagnosed with type 2 diabetes until they were well into middle age. Also, the chart reviews demonstrated that less than 5% of the individuals at the clinic for diabetes treatment were maintaining their Hemoglobin A1c (HgA1c) and blood glucose levels according to the American Diabetes Association criteria for glycemic control. The community needs assessment combined with the chart review provided a better understanding of the health problems of the Hispanic farmworkers. Many of the findings from the initial studies were clarified and refined in the subsequent Binational Study.

In 2001, the HHP engaged in a binational ethnographic project that was designed to describe how Hispanic farmworker families treat acute and chronic illnesses. It was during this research project that we began to understand the true magnitude of the problems associated with diabetes in these communities (Cartwright & Schaper 2002). A team of university researchers, promotores (community health workers) and students went to Dolores Hidalgo, Guanajuato, Mexico, at the invitation of some of the Mexican promotores who were among the first HHP research assistants. The close working conditions and the inter-dependence between the academics and promotores resulted in personal relationships that were based on a real understanding of each other and their importance cannot be overstated.

During the binational ethnographic project, individual treatment-seeking behaviors were described within the context of how families develop strategies to allocate their local and binational resources to obtain treatments and medications. Qualitative interviews describing treatment strategies were carried out with a convenience sample of 150 Hispanic families who were currently employed in agricultural work or in the potato processing plants (100 in SE Idaho and 50 in the sending communities

in Guanajuato, Mexico). Participation rates were better than 95%. These interviews focused on how adults and children in the households used traditional, in-home treatments, local healing experts (*curanderos, parteras, and sobadoras*), medical doctors, and pharmaceuticals for specific illnesses. Current physical status of household members was assessed using basic biomedical tests to screen for diabetes (elevated blood sugars), hypertension and weight problems. Individual's personal understandings or models of diabetes and cancer were also elaborated during the interviews, and, when appropriate, explanatory models were explored for other illness categories that were especially important to a particular individual.

To describe the problem of type 2 diabetes in this population, a significant portion of the qualitative interviews were dedicated to a careful exploration of people's ideas about where diabetes comes from, how it affects them, personal experiences with diabetes in their families, and what it means for individuals in these two communities to have diabetes. Individuals described to us how diabetes came from such things as *herencia* (heredity), *mala nutrición* (poor nutrition), and *gordura* (obesity). These are among the causes recognized by medical doctors and described in other studies (Weller et al. 1999). Individuals in the binational study attributed their diabetes to such ultimate causes as *susto* (fright), *coraje* (anger), and *preocupaciones* (worries). Thematic analysis of *susto*, *coraje* and *nervios* show that these emotions were used to index both a sense of personal stress about individual problems (domestic violence, accidents, etc.) as well as the larger stresses that are so pervasive among these families including having family members “*al otro lado*” (out of the country), fears of deportation, violence experienced in border crossings and discrimination.

Thematic analysis of the interviews also demonstrated that ideas about diabetes were linked with ideas of personal susceptibility; having diabetes was a stigmatized condition that connoted weakness. Individuals who were diabetic were seen as vulnerable to being shocked and physically harmed by situations that others could withstand. For instance, a study participant described how bad news was kept

from a diabetic grandfather for fear of shocking him—the shock could have resulted in his collapsing or dying. Individuals with diabetes were seen as weaker than other people (see also Ferzacca 2000).

One of the tenets of CBPR is that the community has control over the process of identifying health problems; yet sometimes community members do not have adequate information to make informed decisions. In the communities where we worked, it was not uncommon to encounter individuals who did not know whether they had elevated blood glucose levels or increased blood pressure. They also did not understand the health ramifications of having either of these conditions. Once biometric data was provided to them in a non-threatening and easy to understand manner, they became much more interested in learning about diabetes. This binational study provided us with data from one point in time and with a good working knowledge of some of the cultural and social issues surrounding diabetes that needed to be explored in more depth and across time.

### ***Formando Nuestro Futuro: A Five-Year Community-Based Diabetes Research Project***

#### **Study Design**

In problem-posing education, people develop their power to perceive critically the way they exist in the world with which and in which they find themselves; they come to see the world not as a static reality, but as a reality in process, in transformation (Freire 1970, p. 83).

The current diabetes project, *Formando*, has been underway since May 2004. The process of conceptualizing the project as well as the study design, methods, findings and discussion of the first year's results will be included here. The *Formando* project is an example of individual and family level advocacy and research. *Formando* was based on the Freirian concept of dialogic education and community consciousness-raising.

The *Formando* project is being carried out from 2004 to 2009 in the small, agricultural communities of American Falls and Aberdeen, Idaho. A target of 250 individuals aged twelve years and up (out of a total of 1600 adult individuals who self-identified as “Hispanic” on the 2000 Census) will be

enrolled from the Hispanic farmworkers who live (either year-round, or seasonally) in these communities. To be included in the Formando project, at least one individual in the family must be working or have worked in agriculture at some time. Inclusion was broadened to include adolescents and retired adults from the more strict inclusion criteria in our previous studies. This was to provide for a full description of the disease process of type 2 diabetes. Participation rates have been better than 95%, with less than 10 individuals refusing participation.

Individuals are being recruited from several different sources. First, because the HHP has been working in the area for several years, many women and their families are personally known by the promotores. All families whom have had contact with HHP in the past for the Saturday Women's clinics, Salsa Aerobics and research projects and who still are living in the area have been invited to participate in the *Formando* diabetes project. Participation in the healthy cooking and aerobics classes will be taken into account in the final statistical analyses. Participants gave us the names of other families to contact with invitations to participate. This snowball method of recruitment (Rice and Ezzy 1999) has worked well in the past. To recruit from the community at large and avoid selection bias, announcements were made in Spanish and English on radio programs and in local newspapers. Informational flyers about the diabetes project were also posted at local stores, churches, laundromats and restaurants. Local health care providers have also begun to refer individuals and their families who would, for whatever reason, be interested in learning more about diabetes and general health issues. These multiple types of study recruitment are appropriate given the lack of census or other list of Hispanic farmworkers and also recognizing that about ten percent of the farmworkers in this area move frequently (Hunter, Hall, Hearn & Cartwright 2003), thus the need for radio, Spanish language newspapers and flyers at local businesses to make sure that the more mobile part of the population is represented to the fullest extent possible.

### **Data Collection**

The *Formando* study uses quantitative and qualitative methods to document patterns of elevated blood glucose levels, BMIs, and blood pressure often associated with insulin resistance and type 2 diabetes. The data gathering, interviewing and attendant education components are being implemented by the promotores and are designed to encourage community participation in the research project through increasing understanding of the disease process and the ways in which individuals can prevent type 2 diabetes and or care for family members who have the disease. Participants' questions are answered verbally during the home visit and form the basis of subsequent research topics; the questions are analyzed by the HHP team and form the basis of subsequent educational materials. In Year One, the answers were written down by the promotores; in subsequent years the answers will be tape-recorded and transcribed in their entirety. The particular difficulties of living with diabetes are discussed during the home visits. Additionally, the social themes of the stigma of being diagnosed with diabetes and the lack of access to clinical care are also addressed by the promotores. It is through attending to these more social themes, in Freire's (1970) terms, generative themes, that individuals can also become engaged in changing unhealthy aspects of their lifestyles.

To investigate the generative theme is to investigate people's thinking about reality and people's action upon reality, which is their praxis. For precisely this reason, the methodology proposed requires that the investigators and the people (who would normally be considered objects of that investigation) should act as co-investigators (Freire 1970, p. 106).

## **Methods**

*Formando* was conceptualized with the idea of sharing the findings with the participants as the study progressed, as well as through addressing participants' questions during the process. Each study family is visited by the promotores once or twice during the year.<sup>4</sup> At each home visit, all family members

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<sup>4</sup> The *Formando* project was reviewed and approved by the Human Subjects Committee (institutional review board), Idaho State University. Informed consents were written in both Spanish and English and were signed by all participants.

age twelve years and up who wish to participate are provided with their fasting blood glucose levels as well as with their blood pressure, heights, weights and their body mass indices (BMIs). The results of the monitoring values are discussed with the individuals at the time of the visit, and the participants are given their results in writing and are encouraged to take them along to the clinic when they have their next appointment. Any individuals who have abnormal blood glucose or blood pressure readings are double-checked the following day and then counseled to go into the community health clinic if the readings remain above normal. As part of their work at the HHP, the promotores facilitate setting up the clinic appointments for the study participants and will provide interpreting at the medical appointments, if it is needed.

A series of education modules are being presented at each home visit throughout the five-year study. These education modules are based on the questions that the participants had during the previous round of visits from the promotores. Using local illness terms and addressing local ideas pertaining to type 2 diabetes is an important part of creating effective education programs (Brown et al. 2002; Fisher et al. 2002). During each round of visits, different aspects of local perceptions of diabetes are documented through short answer questionnaires as well as through in-depth interviews that elicit culturally specific explanatory models of how diabetes works and how individuals are treating it. All home visits and interviews are carried out by promotores (five females and one male) and, when appropriate, by university faculty and or students who are involved in the project.

The initial interviews were focused on obtaining a detailed understanding of individuals' ideas about where diabetes comes from, how you get it, the bodily symptoms associated with the illness and how it can be treated (see Stein 1985; Schoenberg Amey and Coward 1998). Body image ideas and the cultural meanings of being overweight are also being explored with women and men of various ages (including adolescents) within the households. The condition of obesity has profound ramifications with respect to the abnormal metabolism of blood glucose—less well understood are the social and cultural

meanings associated with being overweight during various times of the life cycle. The following section is a summation of the most seminal results from Year One of the study

## **Findings**

***Quantitative Results.*** The basic, descriptive statistics, including percentage distributions of participants' BMIs, ages and FBGs show that the vast majority of participants were clinically overweight or obese and that weight was greater in older participants.

Table 1 and 2 about here.

Fasting blood glucose levels clearly tended to increase with age. We included the category "High Normal" as an educational tool. While a fasting blood glucose between 91 and 99 mg/dl is not diagnostic for pre-diabetes, individuals with this level who are aware of the relationship between abnormally high FBG and weight gain may be motivated to make behavioral changes. One of the findings from the initial discussions between the promotores and the participants about the basic type 2 diabetes, was that once diagnosed, individuals felt they could do little, and some, because of this hopelessness, did little or nothing<sup>5</sup>; for some, even taking their prescribed medications was seen as useless and being asked to give up one's favorite food or beverage as a punitive measure much resented by both women and men.

***Qualitative Results.*** The analysis of the interviews identified the basic themes from ten short answer interview questions in the Year One encounters. Responses were tallied and grouped together using accepted principles of thematic analysis (Ryan & Bernard 2003). Inter-coder reliability was performed by having the results of the thematic analysis reviewed by all members of the HHP team. Once agreement was attained, field notes and observations were used to triangulate and explain the

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<sup>5</sup> "Ya, me chinge", "Now I am screwed" is a common expression among individuals that have been diagnosed with pre-diabetes and type 2 diabetes in this community. It implies that there is nothing more that can be done.

meanings of the themes. Year Two data will be tape-recorded narratives which should contribute even richer detail.

Participation in *Formando* is open to all community members. Two-thirds of the families in the project had at least one close family member who had been diagnosed with type 2 diabetes or with pre-diabetes in contrast to the result from the original community assessment in which only 5% of families answered that type 2 diabetes was a problem encountered in their families. (Hunter, Hall Hearn & Cartwright 2003). The *Formando* project showed that in many cases, one individual in the household will have been diagnosed with type 2 diabetes many years prior, and the other adults and adolescents in the family did not have even a basic understanding about what diabetes is, its risk factors or how it can be controlled.

Thus, as the HHP team shared the results of the blood glucose tests and discussed how increased weight and increased fasting blood glucose levels are closely related with the *Formando* participants, we examined the reaction of the women in the families—because, in most cases, it is the women who make the changes in the quality and quantity of food consumed. Their husbands, parents, in-laws and the culture itself have expectations of the Hispanic womens' meal preparation, especially when the meals are part of the many celebrations held throughout the year. Not to engage in eating the *carnitas*, *posole*, *tortillas*, *frijoles*, and *pasteles*, is seen as not joining in, as holding oneself aloof. To be on a diet is to “*matarse de hambre*” to kill oneself from hunger. Even the term “healthy cooking”, “*cocinando saludable*”, is associated with food that is overly expensive and lacks flavor and sufficient quantity to render one feeling “full” (*llenarse*). To feel full is important and seen as the marker for when one should stop eating. Until that feeling is attained, individuals believe that they can and should continue eating. In our binational study, many individuals in Mexico were subsisting on a couple of tortillas a day for weeks or months at a time when remittances from their spouses in the U.S. were slow in coming or when subsistence crops failed. As one of the promotores noted, “People believe if they have gone to all the

trouble to come here to the U.S. they should be able to eat well.” The experience of hunger leaves an indelible mark; recent experiences of hunger as well as childhood memories of being hungry contribute to a strong desire to eating one’s fill if the food is available according to the study participants.

Ironically, several of the participants from the aerobics classes who had been successful at losing weight encountered the community opinion that by losing weight they were engaging in an act of vanity which was not consistent with having humility before God. Some of the men pressured their wives not to continue with the aerobics when they saw them losing weight and gaining in self-esteem; conversely, some of the men were supportive of their wives and even began to take interest in getting in shape themselves. Even with their very active agricultural work, 70.4% the men in the study were overweight or obese compared with 78% of the women. Many of the men had the attitude that since they worked hard all day, they did not need to exercise—off-season and weekends were considered times to relax. The complex factors that led to individuals gaining too much weight were embodied in discourses that index religion, immigration, poverty and a woman’s duty to her family. Simply suggesting a low carbohydrate diet and a bit more aerobic exercise was futile, at best.

### ***Sustos, corajes and bilis....***

The first thing I found waiting at home for me after my car accident was my mother with a *te amarga* (bitter tea). She gave it to me so that the *susto* from me wrecking my car wouldn’t give me diabetes or any other health problem. (HHP promotora)

While many individuals in the first round of home-visits knew few specifics about diabetes, other than it was “bad”, “it kills you” and “it is too much sugar in the blood”, over 50% of the participants attributed diabetes to *corajes, sustos, and espantos* (angers and frights). The emotional upsets that individuals feel due to accidents, immigration status, problems with the legal system, poverty and other negative life-experiences were often encoded in their narratives about where their diabetes came from. The generative themes that engage individuals in talking about their diabetes are the narratives

surrounding the *corajes* and *sustos* that are attributed to causing their diabetes. Other generative themes are women's discourses on the meaning of food for themselves and for their families, and the meanings of the social presentations of the body and how that is integrally linked to notions of humility and vanity. These are the themes that will be pursued in the Year Two interviews and discussed and analyzed via age, time in the U.S. and gender. While these themes may well be generalizable to many Hispanic farmworker communities, it is the process of engaging individuals in discussing what the "Latino Folk Illnesses" mean to them at a particular time that is important.

## **Discussion**

The results of the Formando project have demonstrated to community members enrolled in the project and to the HHP team a real need to engage in decreasing the effects of type 2 diabetes in the study communities. Individuals participating in the project now are beginning the process of understanding the relationship between their BMIs and increases in blood glucose levels. Indeed, many of the participants in Formando did not have scales in their homes; we will provide scales to the families in Year Two. The composite quantitative results are being shared with the community during both our health education programs and at community gatherings and health fairs.

The qualitative results indicate that we need to understand better the relationship between culturally acceptable notions of thinness, the meaning of foods and fullness, and how those issues are locally contextualized during social events and family meals. Another important finding was that individuals do not discuss type 2 diabetes within their families, even if family members have the disease. Addressing how type 2 diabetes is experienced by the whole family unit is essential; a lack of interpersonal communication about this disease within families is a real barrier to overcome in changing meal preparation and family physical activities. Both the stigma of diabetes and the lack of information play into this dynamic. The social themes that came out of the interviews show that health practitioners in the U.S. have a real opportunity to explore the lifeworld of Mexican agricultural workers and their families

through engaging in a dialogue about why these individuals think that they have their *sustos*, *corajes*, and *nervios*. It is important to recognize that although many individuals in the Hispanic culture attribute ultimate causation of an illness to these “Latino Folk Illnesses” they are also willing and able to understand the “biomedically-recognized” interactions between diabetes, diet, exercise and their ability to control the symptoms that are associated with type 2 diabetes

## **Conclusions**

Engaging Hispanic women farmworkers and their families in the *Formando* project has been somewhat successful because of the manner in which the past projects were conducted by the promotores and because the promotores come from the community and are ex-farmworkers themselves. Each year the women and their families can see and discuss the results of their biometric tests as well as engage in a more detailed discussion about the prevention and control of type 2 diabetes.

The study had several limitations. One was that the individuals who traveled to work in agriculture were under-represented in the total database. While our existing manner of recruiting has been effective in getting individuals into the Year One phase, it has been more difficult to contact those who do not have permanent houses in the area. While this is a small percentage (less than 10%) of the agricultural workforce, these are also some of the most recent immigrants from Mexico and are also mostly young men. Over 90% of the individuals in this study live in the area all year; thus, the results may not be representative of more mobile farmworker populations. All equipment for measuring heights and weights was checked periodically, but a small amount of error may have occurred from using the scales and stadiometer on different kinds of floors. The self-reported medical information may have also been reported incorrectly.

Brown and Vega’s (1996) protocol for community based participatory research (CBPR) asks community members and researchers to question: how the research will serve the community, how the community will be involved, if the researchers are committed to following-up on their projects, how the

community will be involved in the analysis of the data, how the research will affect perceptions of the community, how the findings will be released, how long term community needs will be addressed, and whether the research is rigorous enough to be a real reflection of the community as well as be acceptable by the scientific community at large. The work done at the HHP so far has demonstrated that the day-to-day negotiation and relationship building is the most fundamental part of being able to continue working in communities over time with the goal of advocating for the cause of the medically underserved.

Research, when couched in terms of advocacy, moves at a different pace than research in other venues (e.g. Minkler & Wallerstein 2003). The recognition of the time it takes to establish real communication, especially with immigrant communities who are displaced and who speak different languages, should be acknowledged by federal funding agencies whose grant cycles are often one or two years in length.

Flexibility within the research process that truly attends to giving the community some say in the direction of the research is imperative; that flexibility along with reliable health information will allow for individuals to identify the research themes that are most meaningful to them.

As for the HHP's work, identifying generative themes that would engage community members in action to become advocates for their own health, we still have much to do. Individuals who are participating in the aerobics classes and the healthy cooking classes are those who are interested in making behavioral changes significant enough to affect their health status. Others are willing to talk, to ask questions and to continue having the HHP promotores take their blood glucose levels, heights, weights and blood pressures. With the continued, sustained efforts of the HHP on this issue, other individuals may feel supported enough to change their eating or exercise habits. Change could also come from a totally different avenue—young adults getting better educations and jobs might facilitate different attitudes about eating and body image. Of course, this could be for the worse, too as in the case of increased consumption of fast food and less physical activity. Advocacy, when it is focused at the level of

helping individuals to understand an issue and to begin to effect the needed changes in their own and their family's health, takes time and patience.

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Table 1. Body Mass Index (BMI) by Age Categories.

BMI	< 21 years	21-39 years	40-49 years	> 50 years	Total
Normal (<24.9)	63.9% (23)	16.4% (11)	16.6% (6)	3.0% (1)	23.8% (41)
Overweight (25-29.9)	19.4% (7)	43.3% (29)	27.8% (10)	48.5% (16)	36% (62)
Obese (>=30)	16.7% (6)	40.3% (27)	55.6% (20)	48.5% (16)	40.1% (69)
Percentage of total responses n=172	100.0% (36)	100.0% (67)	100.0% (36)	100.0% (33)	100.0% (172)

p < 0.001, Spearman Correlation < 0.001

Table 2. Fasting Blood Glucose by Age

FBG mg/dl	<21 years	21-39 years	40-49 years	>50 years	Total
Normal (< 90)	94.1% (32)	83.8% (57)	69.4% (25)	60.6% (20)	78.4% (134)
High Normal (90-99)	5.9% (2)	10.3% (7)	16.7% (6)	9.1% (3)	10.5% (18)

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Pre Diabetes/Type 2 (100 up)	.0% (0)	5.9% (4)	13.9% (5)	30.3% (10)	11.1% (19)
Percental of total responses n=171	100.0% (34)	100.0% (68)	100.0% (36)	100.0% (33)	100.0% (171)

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$p < 0.001$ , Spearman Correlation  $< 0.001$