

Community Partnership Medical Scholars Program Grant Application

Courtney Griffiths, SMS I

Understanding How Golden Valley Community Health Center's Latina Patients Perceive Prenatal Genetic Testing

Academic Year: 2003-2004

Quarter: Summer

75%

Quarter: Fall

25%

Student: Courtney Griffiths

SMS I; Year of Matriculation 2003

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Yes, human subject compliances are required for this project. All human subject compliance information will be submitted to Stanford's Institutional Review Board by 5/1/03. Approval is anticipated by 7/1/03. I have read and accept all obligations related to assuring that all necessary compliances above will be met. In addition, I understand that the information in this proposal and a progress report may be provided to the donor of this project's funding.

Student signature:

Date:

Stanford Faculty Advisor signature:

Date:

A. Public Health Context

In 2001, 21.0% of all births in the United States and 49.5% of all births in California were to Hispanic women (National Center for Health Statistics, 2002; California Department of Health Services, 2003). The increasing number of births to Latina women presents a challenge to health care providers to provide culturally appropriate prenatal care to these communities (NAHH, 2000). Simultaneously, the prenatal testing offered to women during pregnancy is becoming more complex, including maternal serum screening (AFP), chorionic villus sampling, amniocentesis, and ultrasonography. However, very little is understood about Latina women’s conceptualization of prenatal testing, the factors that influence their decisions to undergo or decline such testing, and additional information that would be useful for them in making these decisions. Due to health care providers’ lack of understanding of these factors and a lack of trained genetic counselors, a significant need exists to examine these issues and to develop decision-making tools that are accessible to women of diverse ethnic and educational backgrounds (Rowley, 1995).

B. Literature Review

The decision-making process surrounding prenatal testing is complex. In her decisions to accept or decline prenatal testing, each woman weighs the potential outcomes of this testing and risks associated with it differently, calling into question the usefulness of uniform, age-related testing recommendations for all women and demonstrating a significant need for individualized counseling and decision-making tools to assist women in this process (Kuppermann et al., 1999; Kuppermann et al., 2000). Currently, Latina women are significantly less likely than white women to undergo genetic prenatal testing even when controlling for the effects of educational level, occupation, previous birth history, and history of past elective abortions. However, it is unknown if these differences in genetic testing rates are due to different attitudes towards prenatal testing or if they reflect a lack of clearly understandable, culturally appropriate information regarding this testing (Kuppermann, Gates, & Washington, 1996).

In general, research has shown that women’s decisions about prenatal testing are influenced by their background, values, and cultural beliefs. Moreover, women’s perceptions of prenatal testing are influenced by a multitude of factors including attitudes about disability and abortion, perceptions of the risk associated with testing, partner’s opinion, familiarity with Down syndrome, and perceived usefulness of the test results (Moyer et al., 1999).

Limited research has examined Latina women’s perceptions of genetic testing. Specific factors that may differ between Latina women and women of other ethnic groups include an increased perception that their communities would be accepting of a child with Down syndrome, increased influence of their faith, religion, or religious leaders, decreased likelihood to undergo elective abortions, and increased agreement with the statement that “accepting what is given” is part of their cultural belief system (Learmen et al., 2003; Kuppermann, Gates, & Washington, 1996).

Research has also examined providers’ counseling about prenatal genetic testing and shown that it is rarely sufficient for patients to be able to make informed decisions. In one study, patient-provider discussions about genetic testing averaged 2.5 minutes for women younger than thirty-five and 6.9 minutes for women older than thirty-five and largely focused on the practical details, benefits, and voluntary nature of such testing (Bernhardt, 1998). Another recent study has suggested that developing a more complete understanding of a patient’s underlying values, morals, and ethics may be a more effective strategy for counseling patients about these decisions than the current professional “value-free” model that relies largely on numerical risks (Anderson, 1999). In

summary, the literature demonstrates a clear need for a greater understanding of Latina women's decisions about prenatal testing, tools to assist women in making these decisions, and increased information to assist physicians in providing more individualized and culturally-appropriate education and counseling surrounding these issues.

C. Community Partner

The Golden Valley Health Center (GVHC) is a non-profit community health organization of fourteen clinics in the San Joaquin Valley (Merced and Stanislaus Counties) whose mission is “to improve the health of our patients by providing quality, managed primary health care services to people in the communities we serve regardless of language, financial, or cultural barriers.” GVHC provides a range of services including primary health care, women’s health care, health and nutrition education, and community outreach services to their patients. GVHC provides prenatal care for approximately 1,000 women a year and between 70-80% of their prenatal patients are Latina. Currently, 35% of their patients are farm workers, 22% are uninsured, and 60% of their patients receive Medi-Cal (GVHC, 2003; C. Grover, personal communication, April 16, 2003).

This research project was largely formulated by the organization and is a part of a larger research collaboration between the GVHC and Dr. Miriam Kuppermann at UCSF. Prenatal providers at the GVHC struggle with how to explain prenatal testing (AFP testing, amniocentesis, chorionic villus sampling) in a way that their clients, especially their Latina clients and clients of lower educational backgrounds, can conceptualize and understand. Often, providers feel that they cannot explain prenatal testing to their clients in a way so that women can make informed decisions about accepting or declining these tests. The organization would like this information so they can better communicate with their clients about these issues. Also, these preliminary results will be used to inform Dr. Kuppermann’s development of a computerized decision-making tool for prenatal testing to be used by low-literacy populations.

D. Project Description and Research Hypotheses

This project will examine women’s perspectives of genetic testing during pregnancy and the information they feel they need to make informed decisions about participating in genetic testing. Specifically, pregnant patients of the GVHC will be asked to participate in focus groups and qualitative interviews examining their perceptions and conceptualizations of genetic testing during pregnancy, the factors that influenced their decisions to accept or decline such testing, and what additional information they feel that they need to make informed choices. The information from the interviews/focus groups and accompanying quantitative questionnaires will be analyzed to gain a better understanding of how to present prenatal testing options to GVHC’s patients. See Attachment A for an overall timeline for the project.

The research question for the project is:

- How can the GVHC better assist their pregnant clients in making informed decisions about prenatal testing?

The research objectives for this project are to conduct seven focus groups and corresponding surveys with Latina clients of GVHC:

- To examine how clients of the GVHC conceptualize/understand prenatal testing.
- To explore what clients of the GVHC factor into their decisions to accept or decline prenatal testing.

- To learn what additional information clients of the GVHV would like in order to make more informed decisions about prenatal testing.

Specific research hypotheses:

- Latina clients of GHVC who state that they would be unlikely to terminate a pregnancy will be more likely to decline prenatal testing than similar clients who state they would consider terminating a pregnancy.
- Less-aculturated Latina clients of GHVC may be less likely to undergo prenatal testing than more-aculturated Latina clients of GHVC because they do not view pregnancy as a medical condition requiring treatment but rather a natural process.
- Latina clients of GVHC will be likely to rate the opinions of their families and partners as “very influential” in their decisions to accept or decline genetic testing.
- The acceptance of prenatal testing by Latina clients of GVHC will increase with increased time in the United States.
- The acceptance of prenatal testing by Latina clients of GVHC will increase with previous experiences with prenatal care in the United States.
- Latina clients of GVHC will report feelings of anxiety and worry surrounding the process of prenatal genetic testing, including the decision-making process, the testing itself, and the wait for results.

E. Research Methods

Development Phase

This Spring, with input and guidance from my advisors, I will develop a questionnaire and focus group guide for use in the study. This study is designed to have both a qualitative and a quantitative aspect. This will allow for methodological triangulation and strengthen the study as the qualitative data can provide more in-depth information to inform the quantitative results while the quantitative data will be easier to compare between participants (Heilitzer et al., 1999). In addition, although aspects of health care relating to culture have traditionally been studied using qualitative methods, research has suggested that using a mix of qualitative and quantitative methods may be most appropriate (Meleis, 1996).

The quantitative survey component of the study will contain questions about women’s knowledge, attitudes, and beliefs about prenatal genetic testing. These questions will be drawn from previous studies in this area that have already been validated for use in similar populations. In addition, the quantitative survey will collect basic demographic information as well as information about their pregnancy histories and acculturation.

The qualitative aspect of the study will be comprised of open-ended interviews and focus groups. Interviews will follow the “interview guide approach” so as to increase the comprehensiveness and naturalness of the interview while maintaining some standardization (Patton, 1987). Focus groups will be used so participants can focus each other on the main issues and so participants can help each other discuss the somewhat abstract concepts surrounding prenatal testing (Patton, 1987). The interview and focus group guides will explore women’s understanding of prenatal testing, their decision-making process, and what additional information they feel they need. All Human Subjects/IRB forms will be submitted by the May 1, 2003 deadline.

Recruitment and Data Collection Phase

During the summer, women who are receiving prenatal care at the GVHC will be asked if they are interested in participating in the study by their comprehensive perinatal services providers. I will then contact those who agree to be contacted and tell them more about the project and schedule a time to participate in a focus group or interview. I anticipate conducting interviews/focus groups with a sample of at least thirty-five women. Although my sample will be largely determined by individuals' decisions to participate, my goal is to recruit a heterogeneous sample of women that vary by pregnancy history, acculturation level, and educational background so that common patterns that emerge from the interviews and focus groups may represent shared beliefs or perceptions that could then be used to develop a tool for use with a wider range of women (Patton, 1987). In contrast with the overall sample, individual focus group composition will be as homogenous as possible, matching participants on race, acculturation, pregnancy history, and gestational age (Patton, 1987). I anticipate that I will be spending time at the GVHC this summer meeting their prenatal patients and gaining their trust so that they will be willing to participate in the project.

The majority of the qualitative data will be collected through a series of seven focus groups. However, if focus group recruitment is difficult, qualitative interviews may be substituted for the focus groups after consultation with my advisors. Interviews/focus groups will be taped and conducted in Spanish or English depending on the participants' preference. The quantitative survey will be administered at the same time as the interviews/focus groups are conducted.

Project participants will be pregnant patients of the GVHC who are less than 20 weeks pregnant who agree to participate in the study. Because of IRB guidelines, participants will be limited to women who are at least 18 years old. Given the demographics of the clinic population, it is expected that the majority of participants will be Latina. However, focus groups/interviews will also be conducted with non-Latina patients of the GVHC.

Data Analysis and Results

The qualitative data will be transcribed, translated, and entered into a qualitative data analysis package such as Ethnograph. Data will be first read in entirety to understand its overall context. Codes will be created using an editing-organizing style as themes emerge from the data (Miller & Crabtree, 1999).

The quantitative data will be analyzed using Chi-squared analysis and t-tests as appropriate. The quantitative data examining women's knowledge, attitudes, and beliefs about prenatal testing will be analyzed for variation based on demographic data as well as to gain an underlying understanding of their perceptions of prenatal testing. The qualitative and quantitative data will then be considered together to provide a more complete context of women's perceptions of prenatal testing and the information that they use to make these decisions.

F. Relevance to Community Health

The results of this project could have a significant impact on community health and medical practice. As a growing number of births in California are to Latina mothers, it is critical that their conceptualizations of prenatal testing be better understood so as to be able to provide more culturally appropriate prenatal care. Also, gathering this information is essential to develop simple decision-making tools to aid women in making these decisions. Increased understanding of their choices in

prenatal testing and ownership of their decisions may lead to increased satisfaction and participation in prenatal care overall.

In addition, understanding Latina women’s decision-making processes surrounding prenatal testing can have implications to medical care beyond prenatal testing. These results could also be potentially applicable to other forms of genetic testing and any process that may involve informed consent such as surgery or other medical procedures.

G. Dissemination of Results

The results will be summarized to the community partner through a summary document and/or a presentation of the results depending on the preference of the organization. This document will focus on how to discuss prenatal testing with their Latina clients in ways that are culturally relevant. The results will affect the community in three ways. First, with the results of this project, the clinic physicians will be able to better discuss and explain the options of prenatal testing with their Latina clients. Second, the results will be used to generate a simple and culturally-relevant explanation of genetic testing options for GVHC to provide to their clients. Third, the results of this project will be used to inform Dr. Kuppermann’s development of a computerized decision-making tool to be used by community members to aid in making informed decisions about genetic testing. The results will be disseminated to the Stanford community through a poster at the PRISMS Fall forum and to the larger academy through a manuscript to be submitted to *Women’s Health International* or a similar journal.

H. Learning Objectives

My learning objectives for this project are two-fold. First, I would like to learn more about Latino communities in California as well as Latina women’s conceptualizations and experiences with prenatal care and how to use this information to provide culturally appropriate health care for these communities. Hopefully, this experience will help me to be a better provider to this community in the future and learn how to ask the appropriate questions and listen to the answers in order to provide culturally appropriate care. This learning objective will be met primarily by being able to spend time with Latina women and listening to their perspectives and experiences. Secondly, I would like to improve my research skills especially designing and conducting research in the area of culturally relevant care for Latino communities as well as improve my qualitative and quantitative data analyses skills. For both goals, the guidance of my three advisors as well as the process of conducting the research will aid me in developing these skills. Additional resources that are available to me include the guidance of Dr. Irene Corso, a sociologist who studies cultural competence in medical care and the ability to recruit additional patients, if needed, from the Stanislaus County Health Department due to the relationship between GHVC and the county health department.

I. Student Background

In 2001, I received an MPH in Health Behavior and Health Education from UNC-CH School of Public Health. My master’s thesis was a qualitative evaluation based on conceptual models of cultural sensitivity and empowerment in an HIV prevention training program for Latino lay health advisors. In addition, I have worked as a research assistant and been involved in survey development, survey administration, and data entry and analysis for four different research studies examining Latino health issues. These health issues have included HIV prevention, mental health, access to employment, exercise, and nutrition. My background also includes work in analyzing and

adapting health interventions including computer-tailored health messages to ensure their cultural relevance for Latino communities. Several of these projects also conducted community-based research so I have experience in working and recruiting in community-based settings. In addition, I participated in conducting a community assessment of a rural county in North Carolina and my primary responsibility was recruiting and then conducting focus groups and interviews with Latino community members. My academic background includes coursework in community theory, qualitative and quantitative research methods as well as community assessment. Moreover, for over a year, I worked as a maternity care coordinator at a community health center that served primarily Latina patients. Therefore, I have had extensive field experience with working with Latina women during pregnancy and advising about prenatal care and prenatal testing. I am fully bilingual in Spanish and English.

The project was selected with input from the PRISMS program and the Golden Valley Community Health Center. I was interested in working at a community health center examining an issue surrounding the health of Latina women. Through the PRISMS program, I was connected with GVHC. Dr. Grover and I then discussed the current research needs of his organization and we together agreed upon this research area.

J. Advisors

Dr. Bertha Chen will serve as my Stanford advisor for the project. Dr. Chen is a gynecologist who has experience with Latina women and providing prenatal care. Dr. Chen will help with the general research design aspects of the study and guidance during the study as well as assisting with the Stanford IRB process.

Dr. Chris Grover will serve as my community advisor for this project. In addition to having conducted research with this community through the Golden Valley Community Health Center, Dr. Grover is the most knowledgeable about the specific needs of the organization and the community where I will be working. Therefore, he will be able to provide necessary feedback to make sure the results are useful to the organization and community as well as help me to gain trust and entry into the community.

Dr. Miriam Kuppermann is an Associate Professor in the Department of Obstetrics, Gynecology and Reproductive Sciences at UCSF. Dr. Kuppermann has been investigating women’s preferences and perspectives on prenatal genetic testing for fifteen years and she was the Principal Investigator of a National Center for the Human Genome Research/NIH funded study entitled, “Optimizing Prenatal Testing Decision Making” which recruited and surveyed over 1000 women of various ethnicities about prenatal testing, and she is currently the Principal Investigator for an Agency for Healthcare Research and Quality (AHRQ)- funded study entitled “Evaluation of a Prenatal-Testing Decision Assisting Tool” in which an interactive computerized decision-assisting tool her team developed is being tested in one randomized study of 500 pregnant women, and a second of 145 couples. Dr. Kuppermann has published extensively in this field and will serve as the primary advisor for the content of the study.

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Attachment A: Project Timeline

May 2003

- Human Subjects Approval submitted to the Institutional Review Board
- Survey, Interview guide, and Focus group guide designed.

June 2003

- Preliminary field work in community
 - Meeting providers at Golden Valley Community Health Center
 - Meeting community members
 - Learning about surrounding community

July 2003

- IRB Human Subjects approval received (anticipated)
- Perinatal Service Coordinators begin recruitment
- Surveys, Interviews, and Focus groups begin.

August 2003

- Data Collection continues

September 2003

- Data Collection finishes.
- Interviews/ Focus groups transcribed/translated into English.
- Data analysis

October/November 2003

- Presentation of results at Fall Forum
- Presentation of results to GVHC providers
- Provision of educational tool to GVHC

December 2003

- Draft of manuscript completed