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Issues in Biomedical Research: What Do Hispanics Think?

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Abstract

Objective—To examine barriers and facilitators of biomedical research participation among Hispanics in a rural community in Washington State.

Methods—Questionnaires addressed socio-demographics, health care access, and barriers and facilitators of participation in biomedical studies. This is a descriptive analysis of the findings.

Results—Barriers include the need to care for family members (82%), fear of having to pay for research treatments (74%), cultural beliefs (65%), lack of time (75%) and trust (71%), and the degree of hassle (73%). Facilitators include having a friend/relative with the disease being researched (80%) and monetary compensation (73%).

Conclusion—Researchers should be mindful of these facilitators and barriers when recruiting for biomedical research studies.

Keywords

biomedical research; Hispanic; research ethics; recruitment

INTRODUCTION

Recruitment and participation of minorities in biomedical research is essential to ensure that research findings are applicable to the range of racial/ethnic groups in the United States. Biomedical research refers to basic science research, translational research, and applied research all aimed to further scientific knowledge of medicine and its application. The 1994 National Institutes of Health (NIH) guidelines mandated the inclusion of racial/ethnic minorities in biomedical research; however the mandate has not translated into successful recruitment and retention of racial/ethnic minorities.¹ Racial/ethnic minorities may be reluctant to participate for a number of reasons including low socioeconomic status, poor access to biomedical health care, poorer quality of care, and health disparities.¹ Likewise, minorities often differ from mainstream culture in their perceptions about research and research participation.^{1,2} Relatively little is known about specific obstacles to recruitment, attitudes of patients toward participation, or characteristics of patients who do not participate in biomedical research.²

Only a limited number of studies have considered the impact of biomedical research on the Hispanic population, and even fewer have directly assessed the position of Hispanics on biomedical research participation.³⁻⁶ Although many Hispanics may be willing to participate in biomedical research, when compared to non-Hispanic whites (NHW) they have expressed a higher level of fear and skepticism about biomedical research, after adjusting for age, sex, education, income, and location of assessment.⁴⁻⁶ Hispanic participants were also more likely than NHW to believe that they would be “taken advantage of” as participants of biomedical research study.⁶

Researchers have explored the impact of Hispanic culture on the understanding of biomedical research participant rights.^{7,8} The Belmont Report summarizes basic ethical principles that should be adhered to in human participant trials.⁹ Cultural nuances may inherently contradict the beliefs behind the Belmont Report, such as individual’s sense of autonomy and confidentiality. The importance of family, lack of individualism, and respect for authority, which are common within Hispanic cultures,⁷ are factors that might also undermine research standards set by the Belmont Report. Medical decisions, including participation in a biomedical research study, may require the approval of a family elder or community leader; thus, for Hispanic participants, inclusion of family or community leaders may need to be considered as part of the process of informed consent. Additionally, many Hispanic communities have a sensitivity to class and occupation that may limit the sense of freedom to make an informed decision.⁷ Research staff members may be perceived as persons of authority; thus, the individual may agree to participate because of the position of the person making the request, rather than the individual’s own desire to participate. Finally, the low levels of income found in many Hispanic communities may make even small monetary compensations a form of coercion compromising participant autonomy.⁷

Despite the potential for coercive participation, researchers indicate that members of minority groups are less likely to participate in biomedical research compared to NHW.^{10,11} Hispanics, in particular, have been reported to have a higher level of fear and skepticism about biomedical research compared to their NHW counterparts. Some studies have noted

that Hispanics are more likely to participate in biomedical research studies if the local community is involved in either recruitment and/or the actual research activities, as well as if they are informed of the purpose(s) of the research.^{1,12,13} These findings, though limited, indicate that cultural issues may influence decision making of Hispanic individuals regarding participation in such research. As a result, scientists know less about the Hispanic population than about NHW. This lack of information on the part of researchers has significant implications for the care and treatment of the Hispanic population.

The goal of this paper is to report the results of a study that surveyed Hispanics about their attitudes toward and willingness to participate in biomedical studies as well as socio-demographics and other characteristics of the respondents and explored which of these characteristics are associated with barriers and facilitators of participation in biomedical research. Ultimately, understanding decision making of Hispanic individuals regarding biomedical research participation can help to improve their inclusion and ethical participation in biomedical studies.

METHODS

Setting

This study was conducted in a small rural community in the Lower Yakima Valley of Washington State in 2009. The valley is a predominantly agricultural area that has experienced a sizeable influx of Hispanics since World War II. In the community surveyed, 92% of the residents are Hispanic.¹⁴

Goals

The 3 major goals of the questionnaire were (1) to investigate Hispanic attitudes toward and willingness to participate in biomedical research, (2) to ascertain parents' knowledge and attitudes about the HPV vaccine, and (3) to assess neighborhood characteristics of residents in the community. For this paper, we report only on Hispanic attitudes toward and willingness to participate in biomedical research.

Study Procedures

Five hundred thirty-one community addresses were purchased from a bulk mailing list company, and 400 addresses were randomly selected with the goal of screening 350 households. All households were sent an introductory letter, written in English and Spanish; the letter described the study and provided a local number that could be called if the respondent was not interested in participating. Two weeks following the introductory mailing, a bilingual (English/Spanish) interviewer from the valley approached each household, registered all adult residents (aged 18 and over), and selected one adult for participation in the survey based on having the first birth date after December 31st. To be eligible to participate in the survey, the selected households had to be occupied by at least one Hispanic person aged 18 years of age or older. Participants were provided with a \$10 gift card for their time. All study procedures and survey instruments were reviewed and approved by the Institutional Review Board at the University of Washington. The survey

was prepared in English and Spanish, and respondents could choose their language of interview.

Response Rate

A total of 374 addresses were examined in person. Of these addresses, 228 were ineligible because they were a business, vacant household, invalid address, or household with no Hispanic occupants. An additional 11 addresses could not be contacted after 5 attempts. Of the 135 eligible households, 18 refused to participate; the 117 completed surveys resulted in a participation rate of known eligible households of 87% and an overall response rate of 80%.

Interviewers

Interviewers were working for a larger project at the Center for Hispanic Health Promotion in the Yakima Valley. Their staff is bicultural and bilingual and has received thorough training in community interventions around health promotion activities. For this project, interviewers attended a 2-day training session that addressed in-person interviewing, approaching and registering households, selecting the appropriate respondent, and conducting the face-to-face interview. Trainees went through all the items on the survey and practiced conducting the interview with others. The interviewers also learned procedures for documenting survey dispositions and tracking attempted contacts, as well as maintaining confidentiality of information.

Instrument

The instrument was a 24-item survey that included questions about socio-demographics, health care access, and barriers and facilitators to participating in biomedical studies. The interview took an average of 25 minutes to complete. Building from the Tuskegee Legacy Project Questionnaire,⁷ we asked about a number of barriers to participation, including length of study, familial responsibilities, cultural beliefs, lack of privacy, fear of having to pay for treatment, lack of time, lack of trust, and amount of hassle. Respondents were asked to state whether each would interfere “a great deal,” “some,” or “not at all” with their participation in biomedical research. Facilitators to participation included money, curiosity, encouragement from friends or relatives, participation of friends or relatives, or a friend or relative having the disease being studied. Respondents again answered that an item would encourage them “a great deal,” “some,” or “not at all” to participate.

Respondents were also asked about their trust in doctors, trust in findings from medical research, previous participation in biomedical research, and likelihood to participate in any biomedical study. Response categories ranged from “a great deal,” “some,” or “not at all” (trust in doctors and medical research) to “yes” or “no” (previous participation) to “likely” or “unlikely” (likelihood of participation). Finally, respondents were asked if they thought Hispanics in the United States were more likely to be taken advantage of in biomedical research than were the NHW.

Socio-demographics included self-reported gender, years of schooling, marital status, household income, occupation, and acculturation. Briefly, acculturation is the degree to

which immigrants adopt mainstream values. Acculturation varies by individual and is influenced by degree of interaction with mainstream culture, age at immigration, and reasons for immigrating. Individual acculturation levels may help identify those persons who experience differential risk for disease, have distinct behavioral patterns, or accept biomedical research. The short acculturation scale used in this study was adapted from Coronado et al and measured a 4-item scale that included language spoken, language used in thinking, ethnic self-identification, and place of birth. Individuals received a score from 1 to 4 with a score of 1 indicating low acculturation and a score of 4 indicating high acculturation.¹⁵

Statistical Analysis

Summary statistics for participants were presented to describe the socio-demographic characteristics of the sample. Acculturation was considered low if the participant received a score of 1 and high if the score was greater than 1. We also reported the number and frequency of responses to various barriers and facilitators, and willingness to comply with biomedical test procedures. We explored participant characteristics associated with barriers and facilitators to participation in biomedical research, adjusting for gender and education. Multiple logistic regression was used to assess significant differences between groups with respect to categorical variables, and multiple linear regression was used to assess differences with respect to continuous variables (2-tailed significance level $P < 0.01$). A significance level of 0.01 was used to adjust for multiple comparisons.

RESULTS

Sample Characteristics

Characteristics of our sample are shown in Table 1. Overall, approximately 2 thirds of individuals were women, and the majority (72%) were under 50 years of age, with almost half being under 35. A total of 74% of respondents had not completed high school, and half (50%) had an eighth-grade education or less. The majority (68%) were married or living with a partner. Household income was low, with the vast majority (79%) having a household income of less than \$25,000 a year. About one third worked in agriculture-related occupations. Only 57% of respondents had some kind of health care. Nevertheless, 80% reported having a regular doctor, and 58% had had a physical examination in the past 12 months.

Acculturation

Nearly 80% of respondents answered the survey in Spanish. This was reflected in their answers to the acculturation questions (Table 2). The majority reported using Spanish for speaking (78%), thought in Spanish (71%), self-identified as Mexican (78%), and were born in Mexico (69%). On the short acculturation scale, 66% were categorized with a score of 1 (low acculturation), 4% with a score of 2, 13% with a score of 3, and 17% with a score of 4 (high acculturation).

Barriers to Participation

Barriers and facilitators to participation in biomedical research are described in Table 3. The most often cited barrier that would interfere “a great deal” with participation in biomedical research was a need to care for family members (49%) followed by a fear of having to pay for research treatments (45%).

Several participant characteristics were associated with barriers to participating in biomedical research (Table 3) after adjustment for gender and education. Those who spoke Spanish were more likely than those who spoke English to report that needing to care for family members, cultural beliefs, and a lack of time would interfere a great deal with biomedical research participation, though not statistically significant. Likewise, individuals having a lower score on the acculturation scale (score = 1), indicating lower acculturation, were more likely, though not significantly so, to report needing to care for family members and a lack of time as barriers compared to those with a higher acculturation score (score > 1). Those with a higher income were more likely to cite a lack of privacy/confidentiality (OR=0.30; SE=0.15; P=0.01), fear of needing to pay for research treatments (OR=0.56; SE=0.14; P=0.02), lack of time (OR=0.52; SE=0.13; P=0.01), and lack of trust (OR=0.56; SE=0.14; P=0.02). Finally, individuals who had lived in the community for longer were more likely to cite the degree of hassle as a barrier to participation (P=0.09), though not statistically significant.

Facilitators to Participation

The most commonly reported facilitators to participation (ie, factors that would facilitate participation “a great deal”) included having a close friend with the disease being researched or having family or friends involved in (47%) or encouraging (45%) participation. Over one third (38%) cited that money would facilitate their participation “a great deal.”

Few participant characteristics were significantly associated with facilitators to biomedical research participation (Table 4). Females were more likely than males to report that they would participate if a close friend or relative had the disease although this difference was not statistically significant. There was a significant association between education level and curiosity facilitating participation in biomedical research. Curiosity was a facilitator to participation for the majority of those with the less than a 5th grade education (86%) and greater than high school education (80%). Conversely, curiosity was a facilitator for only 56% of those with a 5th–8th grade and 72% of those with a 9th–12th grade education.

DISCUSSION

Our results support findings from previous studies indicating that Hispanics are willing to participate in biomedical research studies, but there are a number of barriers that prevent their participation.^{2,16–18} The reasons given include needing to care for family members, a fear of having to pay for research treatments, cultural beliefs, a lack of time, a lack of trust, and the degree of hassle. Those who spoke Spanish and those who were less acculturated were most likely to cite needing to care for family members as a substantial barrier to participation, suggesting the potential cultural importance of family over research goals.

Similarly, these groups indicated a lack of time as a barrier to participation. This may be due to family and community responsibilities that individuals are unwilling to sacrifice in order to participate in research. Those who had lived in the community for a shorter amount of time cited a lack of trust as a hindrance to participation, suggesting that building trust and relationships in the community may be associated with trust of the medical system.

Distrust of the medical system among minorities is often discussed in reference to the United States Public Health Service Syphilis Study at Tuskegee.^{5,6,19} One major legacy of that study is reluctance among many African Americans to participate in clinical research studies for fear of future abuses.⁶ Our results suggest that many Hispanic participants may also mistrust the medical system. This could be due to a number of factors, including awareness of the Tuskegee Syphilis Study¹⁷ and other abuses of research in Latino communities, and efforts should be made on the part of researchers in the medical community to build the trust of this population. Other primary barriers emerging from this study include lacking time and having to pay for treatment. This could indicate there is misinterpretation of what a biomedical research project entails and suggests researchers should clearly describe the requirements of research in the consent forms.

Facilitators of participation included having a close friend or relative with the disease being researched, suggesting that if research is relevant to an individual, it will increase the likelihood of his or her participation. Many participants cited money as a facilitator to participation in biomedical research. This raises the concern, especially within low-income communities, that individuals may be coerced into participating, which would compromise participant autonomy. Attention must be paid to sustaining a balance between compromising participant choice and respecting participant's time and contribution to research.

As minorities in general and not only Hispanics have historically been underrepresented in clinical trials, current biomedical research needs to focus on increasing recruitment of minorities for biomedical research. Through the recruitment process, efforts should be continually made to convey the relevance of the study to potential participants, to elicit and address questions and concerns. Training of clinical investigators in cultural competency may address these concerns.¹⁶ This collaborative process is becoming increasingly more indispensable as there are growing anti-immigrant sentiment and efforts to restrict access to services in the United States. This is likely to have a negative impact on the willingness of Latinos to participate in biomedical research.¹⁸

One limitation of this study is that we cannot verify actual research participation by study participants, only willingness to participate if given the chance. In addition, we examined willingness to participate only among those who responded to the survey, a subset of people who are probably more likely to be willing to participate in studies. Despite these limitations, this study provides a unique contribution to the literature by drawing on self-reported information on willingness to participate and attitudes toward participation in biomedical studies among Hispanics in the United States. Recruitment of diverse populations for biomedical research poses several challenges, but is critical to guaranteeing that research findings are applicable to racial/ethnic minorities. Better understanding these

challenges will allow for enhanced recruitment and retention of diverse populations in biomedical research.

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Table 1

Distribution of Acculturation Variables

	N(%)
Language most used for speaking (N=112)	
Spanish	87 (77.7)
English	25 (22.3)
Language most used for thinking (N=117)	
Spanish	83 (70.9)
English	29 (24.8)
About the same in Spanish and English	5 (4.3)
Self-identification (N=117)	
Mexican	91 (77.8)
Chicano	6 (5.1)
Mexican American	13 (11.1)
American	4 (3.4)
Other	3 (2.6)
Place of Birth (N=117)	
Mexico	81 (69.2)
United States	34 (29.1)
Other	2 (1.7)
Acculturation (N=112)	
Low	74 (66.1)
High	38 (33.9)

Table 2

Barriers and Facilitators to Biomedical Research Participation.

	A great deal N(%)	Some N(%)	Not at all N(%)
Barriers			
Length of study	46 (39.3)	47 (40.2)	24 (20.5)
Need to care for family	56 (49.1)	38 (33.2)	20 (17.5)
Cultural beliefs	40 (34.8)	35 (30.4)	40 (34.8)
Lack of confidentiality	37 (31.6)	35 (29.9)	45 (38.5)
Need to pay for research treatment	53 (45.3)	33 (28.2)	31 (26.5)
Lack of time	43 (36.8)	45 (38.5)	29 (24.8)
Lack of trust	36 (30.8)	47 (40.2)	34 (29.1)
Degree of hassle	27 (23.1)	58 (49.6)	32 (27.4)
Facilitators			
Money	44 (37.6)	41 (35.0)	32 (27.4)
Curiosity	35 (29.6)	49 (41.9)	33 (28.2)
Close friends encourage	53 (45.3)	33 (28.2)	31 (26.5)
Close friends participate	55 (47.0)	34 (19.1)	28 (23.9)
Close friend has disease	68 (58.1)	26 (22.2)	23 (19.7)

Table 3

Multiple Logistic Regression Analysis of Barriers to Participation^{a,b}

	<u>Length of study</u>		<u>Need to care for family</u>		<u>Cultural beliefs</u>		<u>Lack of privacy/confidentiality</u>		<u>Need to pay for research treatments</u>		<u>Lack of time</u>		<u>Lack of trust</u>		<u>Degree of hassle</u>	
	Odds Ratio (SE)	P-value	Odds Ratio (SE)	P-value	Odds Ratio (SE)	P-value	Odds Ratio (SE)	P-value	Odds Ratio (SE)	P-value	Odds Ratio (SE)	P-value	Odds Ratio (SE)	P-value	Odds Ratio (SE)	P-value
Age	1.00 (0.02)	0.83	1.00 (0.02)	0.9	1.01 (0.01)	0.98	0.98 (0.01)	0.21	1.03 (0.02)	0.07	0.98 (0.01)	0.24	0.98 (0.01)	0.09	0.99 (0.01)	0.6
Income	1.70 (1.14)	0.43	0.60 (0.35)	0.38	0.80 (0.40)	0.66	0.30 (0.15)	0.01	0.56 (0.14)	0.02	0.52 (0.13)	0.01	0.56 (0.14)	0.02	0.52 (0.13)	0.01
Language (Spanish vs English)	0.49 (0.27)	0.2	0.55 (0.32)	0.31	0.84 (0.41)	0.71	0.71 (0.35)	0.48	0.50 (0.26)	0.19	0.58 (0.30)	0.3	0.50 (0.26)	0.19	0.58 (0.30)	0.3
Insurance (yes vs no)	0.98 (0.47)	0.98	2.05 (1.10)	0.18	1.12 (0.45)	0.78	0.85 (0.34)	0.68	0.80 (0.34)	0.61	1.95 (0.91)	0.15	0.80 (0.34)	0.61	1.95 (0.91)	0.15
Years residence in US	0.99 (0.02)	0.52	0.98 (0.02)	0.37	0.98 (0.02)	0.13	0.98 (0.02)	0.13	1.02 (0.02)	0.37	0.96 (0.02)	0.02	1.02 (0.02)	0.37	0.96 (0.02)	0.02
Acculturation (low vs high)	0.41 (0.24)	0.13	0.36 (0.23)	0.1	0.69 (0.35)	0.5	0.52 (0.27)	0.2	0.66 (0.36)	0.45	0.34 (0.19)	0.05	0.66 (0.36)	0.45	0.34 (0.19)	0.05

^a Comparing those who reported these characteristics affected their likelihood of participation “some” or “a great deal” versus those who reported “not at all.”

^b Adjusted for gender and education

Table 4

Multiple Logistic Regression Analysis of Facilitators to Participation^{a,b}

SES Characteristics	Money		Curiosity		Close friends encourage		Close friends participate		Close friend has disease	
	Odds Ratio (SE)	P-value	Odds Ratio (SE)	P-value	Odds Ratio (SE)	P-value	Odds Ratio (SE)	P-value	Odds Ratio (SE)	P-value
Age	1.01 (0.01)	0.94	0.98 (0.01)	0.97	0.99 (0.01)	0.71	0.99 (0/01)	0.34	0.99 (0.02)	0.5
Income	1.13 (0.32)	0.7	0.76 (0.19)	0.28	1.12 (0.32)	0.7	0.76 (0.21)	0.31	1.06 (0.34)	0.85
Language (Spanish vs English)	1.44 (0.85)	0.53	2.06 (1.20)	0.22	0.80 (0.44)	0.69	1.30 (0.76)	0.7	2.80 (2.30)	0.21
Insurance (yes vs no)	1.15 (0.50)	0.74	1.27 (0.54)	0.57	0.92 (0.40)	0.85	0.89 (0.40)	0.79	2.19 (1.14)	0.13
Years residence in US	1.02 (0.02)	0.31	1.00 (0.02)	0.8	1.01 (0.02)	0.58	1.01 (0.02)	0.69	1.03 (0.02)	0.23
Acculturation (low vs high)	0.99 (0.22)	0.98	1.31 (0.30)	0.23	1.23 (0.29)	0.37	1.17 (0.28)	0.51	1.45 (0.43)	0.21

^a Comparing those who reported these characteristics affected their likelihood of participation “some” or “a great deal” versus those who reported “not at all.”

^b Adjusted for gender and education