

Research Article

Hispanics' Perceptions of Participation in Research Studies and Solutions for Improvement in Participation

Martha O Rojo¹, Jin Jing², Cheryl Wells¹, Jonathan Rodriguez¹ and Latrina Prince^{3*}

¹College of Nursing, University of Arkansas for Medical Sciences Little Rock, Arkansas, USA

²College of Public Health, University of Arkansas for Medical Sciences Little Rock, Arkansas, USA

³Graduate School, University of Arkansas for Medical Sciences Little Rock, Arkansas, USA

***Corresponding author**

Latrina Prince, Graduate School, University of Arkansas for Medical Sciences Little Rock, Arkansas, USA

Submitted: 15 December, 2023

Accepted: 17 January, 2024

Published: 19 January, 2024

ISSN: 2379-0547

Copyright

© 2024 Rojo MO, et al.

OPEN ACCESS**Keywords**

- Hispanics
- Latinos
- Research Challenges
- Research Recruitment
- PerBA

Abstract

In 2022, the Hispanic population in the United States reached 63.6 million, accounting for 19% of the total population. Despite this growth, Hispanics are significantly underrepresented in research studies. The purpose of this mixed-methods study was to evaluate perceived research burden, explore perceptions towards participation in research studies, and solicit strategies to increase research participation in Hispanics. We recruited 25 Hispanic participants' ages 18-65 years from the community. Data were collected using a demographic data sheet, the Perceived Research Burden Assessment (PerBA), and face-to-face interviews. It took about 10 minutes to collect the quantitative data. Interviews lasted 20 to 60 minutes. Audio-recorded interviews were transcribed and translated from Spanish to English by certified translators. Data analyses involved descriptive statistics, the Wilcoxon Rank Sum Test, and thematic analysis. Eighty (n = 20) of the participants were female, 80% (n = 20) spoke a Spanish dialect as their primary language, 43.3% (n = 13) had an annual income of less than \$20,000, 56% (n = 17) had no health insurance, and 49.9% (n = 15) had less than a 12th-grade education. The PerBA revealed three main areas of research participation burden: 1) second thoughts about participating, 2) participation regret, and 3) participation costs. Five major themes emerged from the interviews: 1) lack of knowledge, 2) immigration status, 3) social isolation, 4) language and literacy, and 5) transportation. Two additional themes were academic and community partnerships, and community engagement via social media platforms.

INTRODUCTION

The Hispanic population is the fastest-growing minority group in the United States (U.S.). In 2022, an estimated 63.6 million Hispanics were living in the U.S., comprising 19% of the total population [1], yet their participation in any type of research study is dismal. Ethnic and racial minority groups, such as African Americans (AA) and Hispanics, have historically faced underrepresentation across all types of research, which has been a significant national scientific concern for decades [2]. Despite efforts by the National Institutes of Health (NIH) to increase recruitment by implementing the NIH Revitalization Act of 1993 that mandates the inclusion of minorities in NIH-funded research [3], research participation rates among Hispanics have continued to remain low. For example, recent data shows that Hispanics participated in less than 1% of NIH-funded clinical trials, and their participation in cancer treatment clinical trials was only 2.2%, as compared to 82.9% for Whites and 6.2% for AAs [4-8]. Further, inadequate recruitment of representative study populations presents a significant issue as it hampers

scientists' ability to assess potential variations in drug efficacy or tolerability across subpopulations. This issue becomes even more impactful as cancer treatments increasingly target the molecular characteristics of specific tumor types. Failing to understand the safety and effectiveness of these treatments in different ethnic and racial groups could have significant consequences on patient outcomes.

Lack of diversity in research and/or clinical trials limits the generalizability of findings to minority populations, which consequently impedes the application of innovative treatment options, hinders progress in treatment safety and efficacy among minority groups, and prevents the development of policies and practices tailored to the needs of minority groups. Furthermore, the lack of generalizability of research findings contributes to health disparities [9,10] since minority groups may not have access to or knowledge of new treatments. Despite the need to increase Hispanics' participation in research, there remains a dearth of studies that specifically focus on Hispanics' perspectives towards research studies and possible solutions to engage Hispanics in research [11].

The top factors that researchers have identified as barriers to Hispanics' research participation are: language barriers, fear and lack of awareness, mistrust of the government or institutions, acculturation, and immigration status [12-14]. However, few studies have measured perceived burden quantitatively using validated instruments. In addition, there is limited research on Hispanics' perceptions of research studies and solutions for increasing their participation. To our knowledge, this is the first study to use a validated instrument to assess barriers to research participation in the Hispanic population. The purpose of this study was to explore Hispanics' perceptions about participating in research, assess the level of research participation burden, and solicit recommendations for increasing their participation in research studies to develop recruitment and retention strategies. This formative work will serve as the foundation for developing culturally relevant strategies aimed at increasing Hispanics' participation in research studies to improve health outcomes in this group and reduce health disparities.

METHODS

In this mixed-methods study, we explored Hispanics' perceptions and attitudes toward research studies, elicited solutions to increase their participation, and measured perceived research burden of participation. This study took place in Arkansas, a Southern state that has experienced a 400% growth in Hispanics since the 1990s [1]. Institutional Review Board approval from the researcher's university was obtained prior to recruitment (IRB #206706). We primarily recruited participants at local events commonly attended by Hispanics, including venues such as food trucks and the Mexican consulate in Little Rock, the state's capital city.

To establish trust with the community, the Principal Investigator, who is also Hispanic, visited these locations every week on the same day to recruit and collect data. Further, before contacting the participants, we provided key stakeholders at each recruitment site a comprehensive explanation of the study including the inclusion and exclusion criteria. Between March and July of 2018, purposive and snowball-sampling techniques were used to recruit 25 Hispanics as research participants. Eligibility criteria included being 18 years of age or older, living in Arkansas for at least one year, and self-identifying as Hispanic. The minimum state residency criterion was particularly important since it generally takes at least a year to become comfortable with a new community. Potential research participants were approached and provided a description of the study. The researcher then reviewed inclusion criteria and obtained consent in the preferred language (i.e. English or Spanish).

Data Collection

We used a 12-item demographic data sheet to collect participant demographics, the Perceived Research Burden Assessment (PeRBA), and face-to-face in-depth interviews. The PeRBA was chosen because it was developed to assess the impact of perceived research burden on the recruitment and retention of research participants [15]. The PeRBA consists of 17 items

measured on a 5-point Likert scale ranging from 1 (strongly disagree) to 5 (strongly agree) and has a reliability of Cronbach's alpha rated between .87 and .96. The PeRBA was translated from English to Spanish by certified translators. Subsequently, the translations were back translated to confirm the preservation of the original intent of the questions. Participants were asked to think about the current research study when rating how they felt about each of the perceived research burden items from the PeRBA. Each participant had the option to either complete the survey independently or choose to have the questions read to them by a member of the Spanish-speaking research team.

To ensure that the questions were written in plain language, the health literacy department at the researcher's institution evaluated the PeRBA to determine the readability level (Flesch-Kincaid Grade Level = 8.5). This is the first time that the PeRBA is being used in Hispanic population. Using this quantitative tool to measure burden is important to develop strategies to improve recruitment in this population. This measure will allow researchers to assess specific areas (domains) that influence Hispanics willingness to participate in research studies. After conducting an in-depth literature review, a culturally relevant and plain-language semi-structured interview guide was developed. The guide included questions aimed at capturing knowledge and awareness of research studies, barriers to participation, and strategies to increase research participation. Data was collected using face-to-face interviews. A member of the research team trained in qualitative interviewing conducted all interviews in Spanish. Interviews were conducted in a private area, audio recorded, and uploaded to an encrypted computer; interviews ranged in duration from 20 to 60 minutes. All interviews were de-identified and professionally transcribed, then translated into English and checked for accuracy prior to analysis by listening to the audio.

Quantitative Data Analysis

Data from the demographic data sheet and PeRBA was downloaded to SPSS [16] and analyzed. Descriptive statistics were used to describe the distribution of the burden scores. The mean and standard deviations were generated. Wilcoxon Rank Sum Test was used to compare the scores by years in US, age group, education level, and insurance status. The significance level was set to a p-value of 0.1. Descriptive sociodemographic statistics (i.e. frequencies and percentages) were used to summarize the study sample.

Qualitative Data Analysis

MAXQDA computer software [17] was used to sort, manage, and assist with data analysis. Clarke [18] and Braun's [19] six step data analysis process helped to identify patterns or themes within the interview transcripts. Two researchers coded the first three interview transcripts independently and created a codebook with emergent codes based on the first three interviews. We subsequently used the codebook for analyzing the remaining interviews. One additional member of the research team performed confirmation coding analysis. Codebook

iterations were used to reach consensus on emergent themes and to verify data saturation. The research team met to discuss differences in interpretation of data and resolved all differences using a consensus model.

RESULTS

Eighty percent (n = 20) of participants were female and spoke a Spanish dialect as their primary language with Spanish as their secondary language; 62% (n = 13) had an annual income less than \$20,000; 52% (n = 13) had no health insurance; and 56% (n = 14) had less than a 12th grade education. See (Table 1) for detailed participant demographics.

Perceived Research Burden Assessment

Overall, the mean PerBA results on a scale of 1 (strongly disagree) to 5 (strongly agree) was 2.78. The top three responses

Table 1: Participant demographics (N = 25).

Category	Response	N	%
Gender	Male	5	20
	Female	20	80
	Total	25	100
Age	18-40	19	76
	41-70	6	24
	Total	25	100
Nationality	Mexican	14	56
	Other Latin American Country	11	44
	Total	25	100
Years in the United States	0-15 Years	14	56
	15+ Years	11	44
	Total	25	100
Years in Arkansas	0-15 Years	20	80
	15+ Years	5	20
	Total	25	100
Marital Status	Single	6	24
	Married/living with partner	19	76
	Total	25	100
Education	No formal education	1	4
	Primary to Secondary Education	16	64
	Higher Education	8	32
	Total	25	100
Employment Status	Full time	20	80
	Part time	2	8
	Retired	1	4
	Housewife	2	8
	Total	25	100
Income	\$10,000-19,999	13	52
	\$20,000-39,999	10	40
	\$40,000-69,999	2	8
	Total	25	100
Language	Spanish or Spanish Dialect	25	100
	English	0	0
	Spanish and English	0	0
	Total	25	100
Health Insurance	Yes	12	48
	No	13	52
	Total	25	100

were: second thoughts about the decision to participate in research (Item 13; M = 3.08); regret regarding the decision to participate in research (Item 14; M = 3.04); and transportation costs associated with research participation (Item 17; M = 3.0). The PerBA identifies Item 13 as psychological; Item 14 as psychological; and Item 17 as logistical. The results for each PerBA item are as follows:

- Item 1. I feel that this study's visits might be too frequent. [logistical] (M = 2.84)
- Item 2. I feel that this study's visits might last too long. [logistical] (M = 2.83)
- Item 3. I feel that participating in this study might take too much time away from my friends and family. [logistical] (M = 2.72)
- Item 4. I feel that the researchers might ask me too many questions. [psychological] (M = 2.80)
- Item 5. I feel that the researchers might ask me questions that are too personal. [psychological] (M = 2.72)
- Item 6. I feel that the researchers might call or contact me or my family members too often. [psychological] (M = 2.78)
- Item 7. I feel that my personal information might not be kept private. [psychological] (M = 2.92)
- Item 8. I feel that the research site might be too far away. [logistical] (M = 2.88)
- Item 9. I feel that it might be inconvenient to get to the research center. [logistical] (M = 2.68)
- Item 10. I feel that it might be inconvenient to park at the research site. [logistical] (M = 2.83)
- Item 11. I feel that I may become emotionally upset by the research procedure(s). [psychological] (M = 2.40)
- Item 12. I feel that I may be physically harmed by the research procedures or study intervention. [physical] (M = 2.60)
- Item 13. I feel that I may have second thoughts about my decision to participate in this study. [psychological] (M = 3.08)
- Item 14. I feel that I may regret my decision to participate in this study. [psychological] (M = 3.04)
- Item 15. I feel that this study might take too much time away from my chores and household responsibilities. [logistical] (M = 2.71)
- Item 16. I feel that this study might take too much time away from my, or my family member's job. [logistical] (M = 2.56)

17. Item 17. I feel that it might cost too much to transport myself (or get) to the research center. [logistical] (M = 3.0)

The total burden score is the sum of the scores of all 17 questions. The logistical burden score is the sum of the scores of nine questions (i.e., questions 1, 2, 3, 8, 9, 10, 15, 16, 17). The psychological burden score is the sum of the scores of seven questions (i.e., questions 4, 5, 6, 7, 11, 13, 14). The physical burden score is the score of question 12. We only included the participants who answered all the questions for calculating the total score and the subscale scores. In total, 18 participants answered all the 17 questions, 22 participants answered all the logistical domain questions, 21 participants completed psychological domain questions, and all participants answered the physical domain question. The total burden scores were similar by years in the US, age group, and education level (Table 2). Participants who did not have insurance showed higher total burden score but this was not statistically significant. The average logistical burden score was higher for those who stayed in the US for less than 15 years, those who were younger than 25 years old, and those who completed 12th grade or below. Participants who did not have insurance had significantly higher logistical burden score than those who had insurance. The average psychological burden scores were very similar by years in US. Participants who were younger, and had no insurance showed relatively higher psychological burden score. The physical burden scores were similar by subgroups.

Qualitative Interviews

Factors affecting research participation: Hispanic participants reported a range of issues that served as barriers to participating in research studies and identified two strategies to increase the representation of Hispanics in research studies. Five major themes emerged from the interviews: 1) lack of knowledge, 2) immigration status, 3) social isolation, 4) language and literacy, and 5) transportation.

Two additional themes that involved fostering trust between researchers and the community were academic and community partnerships, and community engagement via social media. See (Table 3) for themes and sub-themes.

Lack of knowledge: Most participants expressed a pervasive lack of knowledge regarding research studies, including their purpose and potential benefits. In addition, most participants had limited or no knowledge of the terms “clinical studies,” “research studies,” or “medical research,” but most had a basic understanding of the term “experiment.” A few participants had some knowledge of the word experiment, but not related to scientific or medical research. Overall, they had negative information regarding experiments.

Furthermore, they lacked any previous exposure to research studies and did not know anyone who had ever participated in any type of research study. One participant stated, “I have never participated in a study nor any of my friends or family members. Not sure what they do to you.” Another participant stated, “Why would I need to participate in research studies? What would I get or how would it benefit anybody?” Lastly, one participant stated, “I don’t know anything about research studies, I have never heard such words. I would participate if I knew what I needed to do.”

Immigration status: Immigration or legal status was frequently cited as a barrier to participation in research studies. Many individuals expressed concerns about their legal status and encountered difficulties in engaging with institutions, specifically government entities, due to a lack of understanding regarding their role and function within society. One participant voiced his concerns as follows: “I am always afraid of sharing any type of information because I don’t know what they will do with it, plus they ask so many questions.”

Some participants were afraid of participating in any type of program since they lacked documentation and lived with fear of deportation; therefore, they were reluctant to participate in any outside activities, including research studies. Another participant stated, “I don’t have my documents. If I participate in any research

Table 2: PerBA Results by Demographics.

Demographic	Logistical domain (n = 22)			Psychological Domain (n = 21)			Physical Domain (n = 25)			Total burden score (n = 18)		
	Sample (n)	Mean (SD)	p-value	Sample (n)	Mean (SD)	p-value	Sample (n)	Mean (SD)	p-value	Sample (n)	Mean (SD)	p-value
Overall	22	24.95 (4.60)	-	21	20.57 (2.38)	-	25	2.6 (0.71)	-	18	49.33 (5.09)	-
Years in US			0.253			0.971			0.383			0.783
< 15	13	26.15 (2.08)		12	20.67 (1.67)		14	2.71 (0.61)		11	49.55 (3.88)	
≥ 15	9	23.22 (6.59)		9	20.44 (3.21)		11	2.45 (0.82)		7	49 (6.93)	
Age group			0.967			0.67			0.455			0.764
18-25	5	26.2 (1.3)		5	21.2 (1.1)		5	2.4 (0.55)		5	49.8 (2.28)	
> 25	17	24.59 (5.17)		16	20.38 (2.66)		20	2.65 (0.75)		13	49.15 (5.9)	
Education			0.124			0.609			0.481			0.718
12th grade or below	16	26.06 (2.93)		16	20.44 (2.56)		17	2.53 (0.51)		15	49.13 (5.58)	
Some college or above	6	22 (6.99)		5	21 (1.87)		8	2.75 (1.04)		3	50.33 (0.58)	
Insurance			0.10			0.175			0.858			0.274
Yes	9	22.67 (5.94)		9	19.67 (2.78)		12	2.58 (0.9)		6	47.17 (5.42)	
No	13	26.54 (2.63)		12	21.25 (1.86)		13	2.62 (0.51)		12	50.42 (4.78)	

Table 3: Major themes and sub-themes from participant interviews.

Primary Themes	Secondary Themes	Sub-Themes
Barriers to Participation	Lack of knowledge	No concept of research
		No history of previous participation
		Do not know anybody that has participated
	Immigration status/legal status	Mistrust in institutions
		Lack of SS#
		Lack of Driver's license
		Fear of deportation
	Social Isolation	Not part of mainstream society
		Living in set neighborhood
	Language & Literacy	Institutionalization of English
		Lack of translation into Spanish
		Plain language translation
		Literacy
	Transportation	Lack of vehicle
		Location of major academic setting
		Convenience
Facilitators to Participation	Academics & community partnerships	Hosting community research events
		Messaging from local institutions & bilingual staff
		Provide culturally relevant research information
	Engagement through social media & traditional venues	Use of newspapers
		Television advertisement
		Use of social platforms
		Testimonial of individuals that have participated in research studies
		Use of Telenovelas to Inform the community
		Engage community leaders

study, could they send me back? Then what will happen to my family?"

Social isolation: Social isolation was described by the participants as an overwhelming barrier that hindered their comprehension and engagement in any type of research study. Participants described how their inability to integrate/assimilate and engage with the broader society restricted their access to potential research study opportunities. Because they lived in neighborhoods where everybody had the same information, most were not exposed to new or different information or opportunities.

Some participants were willing to participate, but because of their social isolation they did not have the knowledge to seek those opportunities. One participant stated, "Living here in the US is good but we are not really part of the bigger picture. This makes it difficult for us to really participate in anything." Another participant mentioned the following: "I feel like people like me don't fit with the bigger society, so we stay away and we miss opportunities." This inability to engage with the broader societal context created limitations, rather than opportunities, to participate in research studies.

Language and literacy: Participants identified English as the predominant language for everyday communication in the U.S. as

a barrier. One participant stated, "Here, very few people speak Spanish. Everywhere we go, everything is in English, and I am not able to understand what is happening." Another participant stated, "It's difficult to want to participate in any research study when you don't understand the language. It's difficult to trust when you don't understand what people are saying." Further, they expressed frustration because, even when they were provided with written information in Spanish, they were unable to comprehend it due to its educational level, rendering the material inaccessible to them. One participant stated, "I don't know how to read or write in Spanish or English. My primary language is a dialect, so even if I am willing to participate in research studies, I cannot do it because I don't understand." Most participants indicated their willingness to participate in research studies if the process was explained in Spanish, in plain language, by someone who understood and respected their cultural background. For example, one participant said, "I would participate, but it would be better if someone that looked like me, and understood my culture, would explain the purpose of research studies. That would help."

Transportation: The lack of transportation was another significant barrier to participants' involvement in research studies. The majority of families in the study sample owned a single vehicle, which was typically utilized by the head of the household for employment-related commitments. One participant stated the following, "I am willing to participate in a study but how will get there? I don't have a car; we have to wait for my husband to go anywhere or I have to ask for a ride." Another participant stated, "We live in a small town. If I need to go anywhere, I have to ask for a ride and we don't have good public transportation in this town."

Academic and community partnerships: Participants expressed a desire for researchers to be actively involved in the community beyond solely seeking to increase participation for their own research studies, indicating the importance of sustained engagement and prolonged involvement in the community. One suggestion was that researchers should participate in local community health fairs throughout the year. One participant described it as follows: "We have many health fairs throughout the year. Maybe researchers could provide information about the benefits of research studies to the community on an ongoing basis and not only when they need us." Some participants recommended fostering ongoing collaborations between academic settings and the community; participants recommended establishing community advisory boards. These boards could serve as platforms for researchers to cultivate relationships and educate community leaders about the significance of research within the Hispanic community. Other participants explained it as follows: "Maybe the researchers can do workshops with our business, religious, and community leaders about research, and they can teach us, but it's going to take time."

Engagement through social media and traditional venues: Participants recognized the potential of leveraging modern technologies, such as social media platforms, to

enhance research participation. Considering the widespread use of smartphones and social media among the Hispanic community, utilizing these channels could be an effective avenue for dissemination of information and teaching about research studies. One participant stated, "Everybody in my community has a phone in their hands. Maybe researchers can do videos about research studies and why they are important." Another recommendation stressed the importance of researchers being actively present in the community, recognizing that face-to-face meetings are essential for establishing trust. It was emphasized that building trust requires time and effort, underscoring the need for researchers or academic representatives to maintain a consistent and ongoing presence in the Hispanic community. For example, one participant stated, "Since we are too afraid to go to you, maybe you can be part of our community, be part of some of our festivities and activities."

DISCUSSION

This is the first study to use the PerBA [15], a validated instrument, with Internal consistency (Cronbach's alpha rated between .87 and .96) to evaluate the perceived research burden among an all Spanish speaking community living a Southern state. Based on our qualitative results, the PerBA was consistent in identifying barriers to Hispanics' participation in research studies. For individual assessment items, participants reported higher level of agreement for two items (psychological and logistical burden): second thoughts about the decision to participate in research (psychological burden); regret regarding the decision to participate in research (psychological burden); and transportation costs associated with research participation (logistical burden).

Psychological Burden

The major PerBA research burden area (domain) that impacted this community was psychological burden. Feedback from the interviews revealed that psychological concerns were related to lack of knowledge regarding research studies. In this sample, most participants did not understand the research process or the need for actively participating in research studies. This further supports the need for exploring ways to educate minority groups on the importance of research, as well as the need for low-literacy research materials to increase understanding, thereby reducing psychological research burden.

Social Isolation and Integration

The social isolation discussed by the participants in this sample is not lack of interaction within the community. They were describing their small social network and infrequent participation in social activities outside of their social networks. The participants were discussing feeling separate from main stream society. This lack of integration was perceived as perpetuating the same information which may impede participation in research studies. There is ample literature on the impact of social isolation and health outcomes, aging, and psychosocial issues in minority groups [20-23]. However, social

isolation and integration have not been thoughtfully explored as a barrier in research participation. Perhaps researchers can use these findings to develop interventions that take into account this phenomenon and consider educating the Hispanic community by using grassroots movements.

Logistical Burden

The second highest PerBA research burden area (domain) was logistical burden. Our study found that participants who had higher logistical burden were those who did not have insurance, had lower education level, or stayed in the US for a shorter time. Logistical issues such as possible transportation costs and other transportation issues were mentioned in the qualitative interviews. This finding may also explain the high rate of lost participant follow-ups in longitudinal studies.

Transportation

Issues with transportation was a significant barrier in this study sample. Most participants voiced concerns about only having one vehicle per household and usually that vehicle was used by the head of the household for employment purposes. Even the basic errands such as going to the grocery store were postponed until the head of the household return from work or they had to ask for a ride from a relative or friend. Our findings are consistent with other studies that found that lack of transportation is a not only barrier to research participation but is a chronic barrier in the Hispanic community [12,24,25]. Research institutions should consider providing or finding strategies to minimize this barrier especially those seeking to incorporate minority groups in their research projects. Researchers should consider budgeting for transportation when working with minority groups. Another strategy would be to identify community leaders that would be willing to transport participants. This would also help to build rapport and research engagement in Hispanic community.

CONCLUSION

Limited studies have reported the research burden assessed by PerBA. One study assessed the perceived research burden using PerBA in Alzheimer Disease and Related Dementias (ADRD) longitudinal studies [26]. This study found that higher burden scores were associated with low participation rate and low retention rate. In addition, our findings were consistent with those of previous studies, i.e. barriers to participation included lack of knowledge, Immigration status, language and literacy, transportation and social isolation [4,27,28]. In 2014, Ceballos et al. established that Hispanics are willing to participate in research studies; yet, their distrust stemmed from lack of information and knowledge, which could be overcome through education. Our findings align with previous research indicating a congruence between participants in this sample and previous participants who were more willing to participate if given the opportunity, but their hesitancy arose due to insufficient knowledge, limited access to credible information sources, and a dearth of opportunities to actively participate. To increase Hispanics' knowledge of research studies should be a priority

to improve their participation in research. This can be done by increasing the presence of researchers in the community. This is a costly and time consuming idea but this might be the only path to increase participation.

Language and literacy are protracted barriers that hinder participation and contribute to increased mistrust among non-English speaking participants. Our findings are consistent with George, et al. [29] who reported that lack of bilingual staff and informational materials in Spanish were barriers to Hispanics' research participation. Similarly, in our study, participants expressed a desire for translated study information in their native language and presented in a manner that was easy-to-understand, i.e., plain language. Furthermore, they emphasized the importance of receiving study information by study staff who shared their cultural background and looked like them. These preferences align closely with the findings of Ford, et al. [30] who reported on the importance of having Spanish-speaking personnel available to assist with the recruitment of Hispanic participants. In addition to language barriers of participants, Chen, et al. [31] reported that despite the federal mandates to include minority groups in research studies, principal investigators are less likely to include participants that do not speak English as their primary language in research studies. In a study conducted by Benavides-Vaello, [32], a significant number of participants expressed concerns about their legal status, leading to misconceptions regarding research participation and immigration. Participants were worried about being reported and uncertain about the role of the institution and immigration authorities. Furthermore, they experienced anxiety and apprehension about participating in studies and the potential risk of not being able to return to their families if immigration enforcement were to occur. These concerns acted as burdens and potentially impacted their willingness to participate in research studies. Similar concerns were reported by Sage, et al. [33], who found that political incivility and immigration concerns impact desirability to participate in research studies. Others studies similar have reported that immigration status impacts Hispanics willingness to participate in research studies. For example, George, et al. [29] found that misconceptions regarding immigration were common among their Hispanic study participants. Further, a recent case study by Benavides- Vaello [32] reported that political issues or political reteric impacted the recruitment of Hispanics in their studies. This highlights the importance of working in the community to buidling trust and rapport in order to clarify the role of health instituions and clear the misconception that are part of the Hispanic community.

Academic and Community Partnerships

The PerBA results provided useful information about feasibility of the study design and overall interest of the study population. Future study procedures should consider tailoring the recruitment and retention strateies at the study design stage to increase research participation. Our findings are consistent with other studies that reported the importance of building relationships between community members and academia to

improve Hispanics' research participation. This fundamental solution proves effective when working with other minority groups [34,35]. Due to the complex socio-political situation of Hispanics living in the U.S., academic settings interested in working with Hispanic communities must invest resources and time to improve research participation. Materials used to recruit participants should be culturally relevant and linguistically adapted for the population of interest. Increased partnerships with the leaders in the Hispanic community such as faith-based organizations, local Hispanic businesses, community event planners, and other established Hispanic organizations will help to build trust and develop long-standing relationships. Bryant et al. [36] was successful in conducting a community needs assessment in Hispanics using the principles of community-based participatory research. In this study, the researchers recruited and trained local faith leaders to collect data. Prior to data collection, a group of 10 faith-leaders participated in a 15-hour face-to-face classroom training in the community. The training was held at local restaurants owned by Hispanics and a Spanish- speaking individual facilitated the trainings. The community's eagerness to learn about research and their receptiveness to researchers were essential factors in building trust and increasing research participation among Hispanics. This study demonstrated that Hispanics are willing to learn and welcome partnerships with academic settings if approached appropriately.

Engagement through Social Media

Another strategy discussed by the participants was the use of social media platforms to connect with the Hispanic community and disseminate information. Using technology and social platforms to provide education about research, as well as its benefits and upcoming research opportunities, has not been extensively used in the Hispanic community [37]. The benefits of these platforms includes accessibility, low cost, and rapid transmission throughout a wide community [38,39]. Further, studies have demonstrated that social platforms can be effective when working with hard to reach populations [37,40]. According to the Pew Research Center [38], in the realm of social media platforms, Blacks and Hispanics emerged as prominent users, with 74% and 72% respectively using Facebook in 2021, in contrast to 67% of Whites. Moreover, Hispanics also stand out as predominant users on various other social media platforms, notably Instagram and WhatsApp. With the evident preference of the Hispanic community for social media sites, these platforms seem to possess significant potential for effectively distributing information and possibility using these venues for recruitment purposes to increase their research participation. Therefore, researchers should incorporate social media platforms into their recruitment strategies when aiming to include Hispanics in their research studies.

LIMITATIONS

These study results should be interpreted with the understanding that the Hispanic population is composed of various subgroups with diverse beliefs, socioeconomic status,

and cultural backgrounds. One limitation is that most of the participants in this sample were foreign-born and living in a rural Southern state. In addition, PeRBA was evaluated in a population of non-Hispanic volunteers. Future studies are needed to examine PeRBA in a larger Hispanic or more diverse population. As a result, findings might not be directly applicable to Hispanics living in large cosmopolitan states such as New York, California, or Texas. Despite these limitations, the findings provide better understanding of the barriers to research participation in Hispanics. Thus, this information could potentially lead to the development of new strategies to improve Hispanics' research participation.

REFERENCES

1. Pew Research Center. U.S. Hispanic population surpasses 60 million in 2019, but growth has slowed. 2019.
2. Davis TC, Arnold CL, Mills G, Miele L. A Qualitative Study Exploring Barriers and Facilitators of Enrolling Underrepresented Populations in Clinical Trials and Biobanking. *Front Cell Dev Biol*. 2019; 7: 74. doi: 10.3389/fcell.2019.00074. PMID: 31114788; PMCID: PMC6502895.
3. Chen MS Jr, Lara PN, Dang JH, Paterniti DA, Kelly K. Twenty years post-NIH Revitalization Act: enhancing minority participation in clinical trials (EMPaCT): laying the groundwork for improving minority clinical trial accrual: renewing the case for enhancing minority participation in cancer clinical trials. *Cancer*. 2014; 120 Suppl 7(07): 1091-1096. doi: 10.1002/cncr.28575. PMID: 24643646; PMCID: PMC3980490.
4. Arevalo M, Heredia NI, Krasny S, Rangel ML, Gatus LA, McNeill LH, Fernandez ME. Mexican-American perspectives on participation in clinical trials: A qualitative study. *Contemp Clin Trials Commun*. 2016; 4: 52-57. doi: 10.1016/j.conctc.2016.06.009. Epub 2016 Jun 27. PMID: 27570845; PMCID: PMC4999069.
5. Hantel A, Luskin MR, Khan I, Warner E, Patel AA, Walsh TP, DeAngelo DJ, Lathan CS, Abel GA. Use, variability, and justification of eligibility criteria for phase II and III clinical trials in acute leukemia. *Haematologica*. 2023. doi: 10.3324/haematol.2023.283723. Epub ahead of print. PMID: 37560812.
6. Kwiatkowski K, Coe K, Bailar JC, Swanson GM. Inclusion of minorities and women in cancer clinical trials, a decade later: Have we improved? *Cancer*. 2013; 119(16): 2956-2963. doi: 10.1002/cncr.28168. Epub 2013 May 14. PMID: 23674318.
7. Parra A, Karnad AB, Thompson IM. Hispanic accrual on randomized cancer clinical trials: a call to arms. *J Clin Oncol*. 2014; 32(18): 1871-1873. doi: 10.1200/JCO.2013.51.7946. Epub 2014 May 19. PMID: 24841978; PMCID: PMC4050202.
8. Salman A, Nguyen C, Lee YH, Cooksey-James T. A Review of Barriers to Minorities' Participation in Cancer Clinical Trials: Implications for Future Cancer Research. *J Immigr Minor Health*. 2016; 18(2): 447-453. doi: 10.1007/s10903-015-0198-9. PMID: 25822567.
9. Allmark P. Should research samples reflect the diversity of the population? *J Med Ethics*. 2004; 30(2): 185-189. doi: 10.1136/jme.2003.004374. PMID: 15082815; PMCID: PMC1733844.
10. Ramamoorthy A, Pacanowski MA, Bull J, Zhang L. Racial/ethnic differences in drug disposition and response: review of recently approved drugs. *Clin Pharmacol Ther*. 2015; 97(3): 263-273. doi: 10.1002/cpt.61. Epub 2015 Jan 20. PMID: 25669658.
11. Martinez-Hollingsworth A, Hernández J, Edwards C, Partlow K. Mural Painting to Collect Sensitizing Data and Encourage Research Participation Among U.S. Latinos. *Health Promot Pract*. 2022; 23(5): 766-776. doi: 10.1177/15248399211038901. Epub 2021 Sep 23. PMID: 34553625.
12. Hildebrand JA, Billimek J, Olshansky EF, Sorkin DH, Lee JA, Evangelista LS. Facilitators and barriers to research participation: perspectives of Latinos with type 2 diabetes. *Eur J Cardiovasc Nurs*. 2018; 17(8): 737-741. doi: 10.1177/1474515118780895. Epub 2018 Jun 11. PMID: 29886773; PMCID: PMC8096125.
13. Rodríguez-Torres E, González-Pérez MM, Díaz-Pérez C. Barriers and facilitators to the participation of subjects in clinical trials: An overview of reviews. *Contemp Clin Trials Commun*. 2021; 23: 100829. doi: 10.1016/j.conctc.2021.100829. PMID: 34401599; PMCID: PMC8358641.
14. Shea L, Pesa J, Geonnotti G, Powell V, Kahn C, Peters W. Improving diversity in study participation: Patient perspectives on barriers, racial differences and the role of communities. *Health Expect*. 2022; 25(4): 1979-1987. doi: 10.1111/hex.13554. Epub 2022 Jun 28. PMID: 35765232; PMCID: PMC9327876.
15. Lingler JH, Schmidt KL, Gentry AL, Hu L, Terhorst LA. A New Measure of Research Participant Burden: Brief Report. *J Empir Res Hum Res Ethics*. 2014; 9(4): 46-49. doi: 10.1177/1556264614545037. PMID: 26125079; PMCID: PMC4487419.
16. IBM Corp. SPSS Statistics for Windows, version 28.0. In IBM Corporation. 2021.
17. VERBI Software. MAXQDA 2022 [computer software]. In maxqda.com 2021.
18. Clarke V, Braun V. Teaching thematic analysis: Overcoming challenges and developing strategies for effective learning. *Psychologist*. 2013; 26: 120-123.
19. Braun V, Clarke V. Using thematic analysis in psychology. *Qualitative Research in Psychology*. 2006; 3(2): 77-101.
20. Brummett BH, Barefoot JC, Siegler IC, Clapp-Channing NE, Lytle BL, Bosworth HB, et al. Characteristics of socially isolated patients with coronary artery disease who are at elevated risk for mortality. *Psychosom Med*. 2001; 63(2): 267-272. doi: 10.1097/00006842-200103000-00010. PMID: 11292274.
21. Cornwell EY, Waite LJ. Social disconnectedness, perceived isolation, and health among older adults. *J Health Soc Behav*. 2009; 50(1): 31-48. doi: 10.1177/002214650905000103. PMID: 19413133; PMCID: PMC2756979.
22. Steptoe A, Shankar A, Demakakos P, Wardle J. Social isolation, loneliness, and all-cause mortality in older men and women. *Proc Natl Acad Sci U S A*. 2013; 110(15): 5797-801. doi: 10.1073/pnas.1219686110. Epub 2013 Mar 25. PMID: 23530191; PMCID: PMC3625264.
23. Tibiricá L, Jester DJ, Jeste DV. A systematic review of loneliness and social isolation among Hispanic/Latinx older adults in the United States. *Psychiatry Res*. 2022; 313: 114568. doi: 10.1016/j.psychres.2022.114568. Epub 2022 Apr 20. PMID: 35643058.
24. Barajas JM, Chatman DG, Agrawal AW. Exploring bicycle and public transit use by low-income Latino immigrants: A mixed-methods study in the San Francisco Bay Area. 2016.
25. Williams E, Pollack S, Luna IC, Lopez R. Transportation Dilemmas Facing Low- Income Latinos in Massachusetts. 2014.
26. Gabel M, Bollinger RM, Knox M, Coble DW, Grill JD, Edwards DF, et al. Perceptions of Research Burden and Retention Among Participants in ADRC Cohorts. *Alzheimer Dis Assoc Disord*. 2022; 36(4): 281-287. doi: 10.1097/WAD.0000000000000514. Epub 2022 Jul 6. PMID: 35796752; PMCID: PMC9712497.

27. Heredia NI, Krasny S, Strong LL, Von Hatten L, Nguyen L, Reininger BM, et al. Community Perceptions of Biobanking Participation: A Qualitative Study among Mexican-Americans in Three Texas Cities. *PublicHealthGenomics*. 2017; 20(1): 46-57. doi: 10.1159/000452093. Epub 2016 Dec 8. PMID: 27926908; PMCID: PMC5453816.
28. Martinez P, Cummings C, Karriker-Jaffe KJ, Chartier KG. Learning from Latino voices: Focus Groups' Insights on Participation in Genetic Research. *Am J Addict*. 2017; 26(5): 477-485. doi: 10.1111/ajad.12531. Epub 2017 Apr 4. PMID: 28376266; PMCID: PMC5529223.
29. George S, Moran E, Duran N, Jenders RA. Using animation as an information tool to advance health research literacy among minority participants. *AMIA Annu Symp Proc*. 2013; 2013: 475-484. PMID: 24551351; PMCID: PMC3900192.
30. Ford ME, Siminoff LA, Pickelsimer E, Mainous AG, Smith DW, Diaz VA, et al. Unequal burden of disease, unequal participation in clinical trials: solutions from African American and Latino community members. *Health Soc Work*. 2013; 38(1): 29-38. doi: 10.1093/hsw/hlt001. PMID: 23539894; PMCID: PMC3943359.
31. Chen A, Demaestri S, Schweiberger K, Sidani J, Wolynn R, Chaves-Gnecco D, et al. Inclusion of Non-English-Speaking Participants in Pediatric Health Research: A Review. *JAMA Pediatr*. 2023; 177(1): 81-88. doi: 10.1001/jamapediatrics.2022.3828. PMID: 36315130.
32. Benavides-Vaello S. Determining diabetes and hypertension healthcare needs for low- income Hispanics in Montana: A participatory action approach. 2017.
33. Sage R, Benavides-Vaello S, Flores E, LaValley S, Martyak P. Strategies for conducting health research with Latinos during times of political incivility. *Nurs Open*. 2018; 5(3): 261-266. doi: 10.1002/nop.2.166. PMID: 30062018; PMCID: PMC6056452.
34. Julian McFarlane S, Occa A, Peng W, Awonuga O, Morgan SE. Community-Based Participatory Research (CBPR) to Enhance Participation of Racial/Ethnic Minorities in Clinical Trials: A 10-Year Systematic Review. *Health Commun*. 2022; 37(9): 1075-1092. doi: 10.1080/10410236.2021.1943978. Epub 2021 Aug 22. PMID: 34420460.
35. Turin TC, Chowdhury N, Rumana N, Lasker MAA, Qasqas M. Partnering with organisations beyond academia through strategic collaboration for research and mobilisation in immigrant/ethnic-minority communities. *BMJ Glob Health*. 2022; 7(3): e008201. doi: 10.1136/bmjgh-2021-008201. PMID: 35332054; PMCID: PMC8948381.
36. Bryant K, Pro G, Rojo M, Patel J, Haynes T, McElfish P, et al. Identifying community needs of the Hispanic faith community to develop a research agenda. *Public Health Nurs*. 2022; 39(1): 33-39. doi: 10.1111/phn.12973. Epub 2021 Sep 21. PMID: 34547116; PMCID: PMC9291199.
37. Darko EM, Kleib M, Olson J. Social Media Use for Research Participant Recruitment: Integrative Literature Review. *J Med Internet Res*. 2022; 24(8): e38015. doi: 10.2196/38015. PMID: 35925655; PMCID: PMC9389385.
38. Pew Research Center. Social media use in 2021.
39. Sledzieski N, Gallicano TD, Shaikh S, Levens S. Optimizing Recruitment for Qualitative Research: A Comparison of Social Media, Emails, and Offline Methods. *International Journal of Qualitative Methods*. 2023; 22.
40. Martinez O, Wu E, Shultz AZ, Capote J, López Rios J, Sandfort T, et al. Still a hard-to-reach population? Using social media to recruit Latino gay couples for an HIV intervention adaptation study. *J Med Internet Res*. 2014; 16(4): e113. doi: 10.2196/jmir.3311. PMID: 24763130; PMCID: PMC4019772.