

PERCEPTIONS FROM LATINO AND AFRICAN AMERICAN OLDER ADULTS ABOUT BIOLOGICAL MARKERS IN RESEARCH

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Although older adult minorities face disparities in health and health care, they continue to be underrepresented in health research. Studies with biological markers of health often lack representation of older minority adults. The purpose of this study was to describe perceptions of biomarkers among ethnic minority seniors who might participate in studies of biological markers of health and to document barriers and facilitators to acceptance of biomarkers. Six focus groups (3 of Spanish-speaking Latinos and 3 of African Americans) were conducted in three community senior service organizations (two senior centers and one church). Ten semi-structured interviews were conducted to support and augment focus group data. Seventy-two community-dwelling minority older adults aged 62 years and older and 10 community stakeholders participated. A community-based partnered research approach was used and two community partners participated in the analysis and interpretation of results. Standard qualitative content-analysis methods were used to identify and organize themes in domains. Focus group participants were 49% Latino and 51% African American. Results included barriers: 1) mistrust, 2) fear of specimen collection/storage, 3) perceived harms, 4) competing demands, and 5) costs. Older Latinos cited issues of language as barriers to awareness and acceptance of biomarkers. African Americans had concerns over perceived harms of biomarkers. Facilitators to acceptance of biomarkers were community engagement through church and community leaders. Older Latino and African Americans identified many barriers and facilitators to the collection and storage of biomarkers. Participants identified community-partnered recommendations to overcome barriers to the acceptance, collection, and storage of biomarkers. *Ethn Dis.* 2015;25(3):355-362.

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INTRODUCTION

There are 8.1 million racial and ethnic minority older adults in the United States comprising 20.4% of the population aged >65 years.¹ This number will rise dramatically between 2012 and 2030 with minority older adults projected to increase by 125% compared with 54% for older non-Hispanic Whites.² African American and Latino older adults are disproportionately affected by chronic diseases, such as hypertension and diabetes³ and report lower levels of health-related quality of life.^{4,5} From 2009 through 2018 alone, disparities will account for \$220 billion of the nation's rising Medicare costs.⁶

Despite significant demographic projections and associated increases in disease burden and cost, Latino and African American older adults remain underrepresented in research studies that collect and measure bio-

logical markers of health^{7,8} raising the concern that the medical community will lack critical empiric data needed to inform treatment decisions. In addition to race-ethnicity,^{9,10} environmental and social factors¹¹ may also contribute to variation in biological marker levels and health outcomes for older minorities.¹²⁻¹⁴ Lack of knowledge and skills to culturally tailor outreach and recruitment methods targeting older Latinos and African Americans may leave investigators unprepared to effectively recruit in these minority communities.^{15,16}

Previous studies have identified socioeconomic constraints, mistrust of health care and researchers, knowledge of historically important research, and language and literacy as important factors for the low participation of young and older adult ethnic minorities in general research studies.^{16,17} Fewer studies have focused on older ethnic minority adults.¹⁸ One study of Latino and African American older adults focused on health-related quality of life and attitudes about their participation in general health research.¹⁸ Some evidence suggests that training staff to address culturally and linguistically sensitive participant concerns helps to improve participation in the collection of specimens such as dried blood spots.¹⁹ More research is needed from ethnic minorities.

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This exploratory study used a community-partnered approach to understand perspectives of older Latino and African American adults and community stakeholders concerning biomarkers collected in research. In particular, we were interested in opinions about the collection and storage of the biomarkers.

METHODS

Approach

A community-participatory partnered research approach was used throughout the study and was critical for successful recruitment and data collection.^{20,21} The study aims and approach were vetted for appropriateness and relevance to community by the Los Angeles Community Academic Partnership for Research in Aging (LA CAPRA) Center and the UCLA Resource Center for Minority Aging Research/Center for Health Improvement of Minority Elderly (RCMAR/CHIME) joint Community Action Board.

Conceptual Framework

We apply the conceptual framework by Ford et al¹⁷ of barriers/promoters to recruiting underrepresented populations to cancer trials to guide our research about barriers/facilitators to acceptance of biological markers in research among older Latino and African American adults.²² The framework posits that first, potential participants have to be aware of studies and have an opportunity to participate. Barriers/facilitators to participation in research are factors inherent in study design that can be

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categorized according to the predicted effects on awareness, opportunity, and acceptance/refusal of enrollment.²³ In this framework, age, sex, language, income, SES, education, and culture are factors that serve as moderators to awareness, opportunity, and acceptance/refusal barriers/promoters.

Data

We conducted six focus groups of older adults (three with Latinos and three with African Americans) and 10 one-on-one semi-structured interviews with key stakeholders. The UCLA Human Research Protection Program approved the study and participants received a \$20 incentive. The underpinning for the focus group and interview questions was the conceptual framework¹⁷ and published literature.^{16,18,24-26}

Focus group participants consisted of a convenience sample of 72 community-dwelling Latino and African American older adults. Inclusion criteria were: aged >62 years;

the ability to consent to the study as determined by a trained research assistant; the ability to sit for one hour; and not institutionalized. For the African American groups, the ability to speak English was in the inclusion criteria. For the Latino groups, the ability to speak Spanish was in the inclusion criteria. Seventy-two potential participants (88%, 72/82) were eligible and provided written consent. We ended recruitment when we exhausted the full range of experiences and reached saturation of ideas.

Ten individual interviews were conducted with a convenience sample of community stakeholders to supplement the data from the focus groups. We included stakeholder interviews because research has shown that a very important strategy to successful recruitment of minorities into clinical trials is to understand community and social-cultural networks and to include community leaders in the research process.²⁵ We identified stakeholders that were community program directors, senior center staff, and community liaisons and were recruited through referrals from leaders within senior service agencies.

Focus Groups

Focus groups were approximately one hour in duration and audio recorded. They ranged in size from 8-12 participants, were segmented by race-ethnicity and the groups for Latinos were conducted only in Spanish. The group facilitators were trained and experienced with interview techniques and used an interview guide containing questions and prompts.

In the group discussions, facilitators explained that biomarkers of

health could be measurements such as blood pressure, pulse, and weight. They also identified blood analysis or genetic testing of any kind, such as DNA testing, as examples of biomarkers of health. Finally the respondents were informed that radiology studies such as CT scans, MRIs, or other procedures that measure something about their health would fall into the category of biomarkers of health. Participants were asked to share their perceptions of the collection of biomarkers, to identify what they thought were the most critical factors for the acceptance of biomarkers, how biomarker research protocols could be improved, how the participation of seniors from racial and ethnic minority groups could be increased, and how the quality of experience of collecting biomarkers could be enhanced for older adult minorities.

Interviews

We conducted 10 one-on-one semi-structured interviews with community stakeholders. Potential participants were identified by our community partners and the LA CAPRA community action board.²⁷ The stakeholders were knowledgeable about health issues for ethnic minority older adults and had experience in the local and regional aging community service sector. Thirteen potential participants were identified and we were able to schedule interviews with 10. One researcher (GM) conducted the interviews with a protocol including probes that were only asked if needed. The interviews took place in person or by phone and lasted 35 minutes on average. Eighty percent of the interviews were conducted in person. We

Table 1. Characteristics of focus group participants

Characteristic	N	%
Number of focus groups	6	--
Total number of participants	72	
Mean number of participants per group	12	--
Race-ethnicity		
Latino	35	49%
African American	37	51%
Gender		
Female	51	71%
Male	21	29%
Spanish language fluency	36	49%

prompted interviewees to comment on their experience with research involving the collection of biomarkers, what they perceived as the most worrisome issues regarding the participation of minority seniors in biomarker research, how satisfied they were with ethnic-specific community organizations' experiences with biomarkers, and whether they felt there was a need for research protocols to change to meet the needs of minority seniors.

Analysis

Descriptive statistics were used to calculate frequencies for the participants' demographic characteristics.

All focus group discussions and interviews were transcribed verbatim and de-identified. Two researchers (CM, GM) and two community members with expertise in minority aging independently analyzed the transcripts for themes. The reviewers read the transcripts several times and used standard qualitative content-analysis methods to identify recurring concepts using the conceptual framework developed by Ford et al as a guide.²⁷ Concepts were categorized into codes that were then used to label discrete quotes in the transcripts.

An open coding method was ini-

tially employed by reviewers. Any discrepancies in coding of the transcripts were adjudicated by an investigator on the team. Based on these independent analyses, a comprehensive code book consisting of a list of all codes generated was collaboratively developed and used by the team in the final round of reviewing. Finally, we put the codes into broad domains (awareness, opportunity, and acceptance barriers/facilitators) as guided by the conceptual framework. The focus group transcripts were coded first and the themes were corroborated in the interviews.

Researchers who participated in the analysis have training in medicine, sociology,²⁸ community research,²⁹ public health, geriatrics, gerontology, and health services. ATLAS.ti software was used to organize the data.

RESULTS

Focus group participants were 49% Latino, 51% African American, and 71% were female. Table 1 lists participant characteristics.

We identified 29 themes and categorized them into the three overarching domains according to the

conceptual framework we adapted.¹⁷ Tables 2-4 list the themes under the three domains: (1) awareness, (2) opportunity, and (3) acceptance/refusal.

Barriers to Awareness, Opportunity, and Acceptance/Denial of Biomarkers

Barriers to Awareness

We identified four themes relating to participants' awareness of biomarkers: language, health literacy, cultural knowledge, and education (Table 2). Participants reported a lack of understanding of the topic, with language and health literacy being common barriers to awareness. A Latino participant highlighted the language barrier by stating, "People

have given classes to this community about biomarker research, but they did it in English so we still don't understand it well." This participant went on to explain that written material about biomarkers was difficult to read and understand. Culturally, most participants attributed a general negative connotation to the words "biomarker" and "biomarker research." One African American participant stated, "I hate to say this. I just think of a rat. And there's no lab rat that you don't inject them with something. This is what I think about when you mention biomarkers."

Barriers to Opportunity

Themes identified as barriers to opportunity to accept biomarkers

were communication, respectfulness and courtesy, costs, and specimen collection burden. Participants mentioned lack of professionalism, poor communication (eg non-transparent explanations), and specimen collection burden as negative experiences in previous biomarker research (Table 3). Statements about poor communication were attributable to older Latinos and African Americans in equal numbers. Older Latinos commonly cited negative issues of language as it applies to explanations of biomarker processes and protocols. One Latino participant stated, "There were instances where people walked out because the research staff did not speak Spanish. What a joke because we couldn't understand what biomarkers they were referring to."

Barriers to Acceptance

Table 4 lists themes (mistrust of health care, mistrust of investigators, fear of bio-specimen collection and storage, perceived harms, time, and transportation) and illustrative quotes of barriers to acceptance of biomarkers. Participants were aware of unethical research studies (eg, Tuskegee syphilis experiments and Guatemala STD experiments) conducted in minority communities.

Fear of bio-specimen collection and storage was a barrier to acceptance of biomarkers. We identified concerns around needles and blood draws, legal responsibilities of bio-specimens collected, and repeated bio-specimen collection. Participants felt mistrust that their biologic specimens would be mishandled and potentially used against them or to further stigmatize their communities

Table 2. Illustrative quotes of barriers/facilitators to awareness of biological markers

Barriers to awareness

Language

"Sometimes [staff] is required to be bi-lingual, which is another issue. I would say 90% of our participants are Spanish speakers and even if they don't understand it they might not want to say anything...they're afraid."

Health Literacy

"Why not just simplify it? Just have it compact where you don't have to have 20 or 30 pages to figure out what [investigators] will be collecting and studying."

Cultural knowledge and beliefs

"They said things like we don't know what they're going to do with that [biomarker] information so I'd rather not participate."

Education about biomarkers

"There are a lot of so called 'biomarkers' that I have never heard of. [Investigators] need to educate us on this, but not in a condescending way. But in a good and productive way."

Facilitators of awareness

Personal health

"It's about me and my health and what I want to know about myself. That's why I don't mind participating in [biomarker] research."

Previous participations

"I participated in a diabetes study where I had to do several blood draws. It was a good experience because they also learned about taking care of me. I would participate again."

Knowledge (transparency)

"[Investigators] just take information and we never find out, and that's kind of a bummer..."

"I think we have to be very, very clear about the guidelines, about it's [biomarkers] long range impact. What are you using this biomarker information for?"

Cultural sensitivity

"There are many diseases in this community and researches need to know what's important to us. If they want us to participate, then they need to know what diseases are in community."

Table 3. Illustrative quotes of barriers/facilitators to opportunity to participate in studies of biological markers

Barriers to opportunity

Communication

"They took about seven tubes of blood and never told me anything about the study results. What exactly is going to be collected and studied?"

Professionalism

"We had an incident here...you had a young man collecting [biomarkers]...he spoke down...he didn't understand...when we tried to correct him on his wording, he got more agitated and angry."

Costs (wages, parking)

"They need to pay for my parking. I'm going to give them [bio-specimens] so they could pay for that."

Specimen collection burden

"I have to see them take it [specimen collection equipment] out of the wrapper. Wash their hands before you even touch me. It makes a difference to me if I see this."

Facilitators of opportunity

Protocol characteristics

"I need to know exactly what you want to do with my [bio-specimen] samples. Where is it going to be stored? Are you going to watch it 24 hours a day?"

Consent forms

"It was too much for one hour... I can't do it. I have to take it [consent] home, read it carefully then."

Translation

"And sometimes they put, for example, a translation from English to Spanish and it sounds like... it's not in English but also not in Spanish. I can't tell what they want to collect from me."

Staff from community

"There are people in the community that help, churches and community leaders. They can show investigators the ropes. Especially with complicated studies that ask for [biomarkers] samples."

Appropriate presentations

"If it's for seniors it needs to involve seniors who reflect the group that you're appealing to because it's very easy to dismiss it if they can't relate... I think a graphic or a little movie, we'd like to see to really grasp. So that helps a lot."

Meeting investigator/team

"If they are asking for a lot, like my blood samples, it would be nice to meet the investigators and team before. Who exactly is going to be drawing my blood or collecting my saliva sample?"

Community leaders

"We have ministers and black community leaders that you could contact and maybe hold a seminar on biomarkers studies." "If you talk to the ministers, they know what's going on in the community." "I think they should be familiar where they're coming and who's calling the shots."

in the future. One female participant said, "I feel that you're collecting information that in the long run may be held against me." Another focus group participant added, "Blood is a marker of my DNA and that information can be shelved out to the wrong people." Perceived harms like the discovery of new illness or experimental drugs and radiation from blood draws or imaging were mentioned in focus groups as important factors for not participating in biomarker research. One participant mentioned, "Ignorance is a bliss... so why do I need to go to you to tell me that something is wrong with my health" and another stated that. "I wouldn't participate if there were risks

of side effects such as those from radiation or medication. How do I know that you will not inject me with something when you collect your specimen?"

Facilitators of Awareness, Opportunity, and Acceptance/ Denial of Biomarkers

Facilitators of Awareness

Themes identified as facilitators to awareness of biomarkers were interest in personal health, previous participation, knowledge of biomarkers, and cultural sensitivity. Focus group participants thought it was important to participate in biomarker research because they would gain important

information about their personal health. Other facilitators to awareness of biomarkers were knowledge about the biomarkers and cultural sensitivity. Both Latino and African Americans, and stakeholders cited that transparency in the form of sharing results of study was important and influenced their participation in research.

Facilitators of Opportunity

We identified themes relating to facilitators of opportunity to accept biomarkers: protocol characteristics, consent forms, translations, staff from community, appropriate presentation, meeting PI and team,

Table 4. Illustrative quotes of barriers/facilitators to acceptance of biological markers

Barriers to acceptance

Mistrust of healthcare

“Do you know there are some insurance companies that look for [biomarker] information so they don’t have to pay for your policy if you were to die? That’s why I don’t like to give my [specimens].”

Mistrust of investigators

“You know what happened during the 30s, 20s when they went into these certain communities and experiment with these people...And these people got a disease and transferred it into their families.”

“I think it helps if you have a Latino researcher that is familiar with the culture, not a third generation Latino born here that has no clue.”

Fear of bio-specimen collection and storage

“No blood. And the fact that you’re going to store my blood? That’s not going to work.”

“That’s a red flag. No I would not participate. Some seniors are a hard stick. So maybe a finger stick...”

“I wouldn’t be comfortable with them drawing blood here because...that becomes a liability and my job is to prevent that.”

Perceived harms

“Collecting research [bio-specimens] is painful. When I get blood drawn in my doctor’s office, they always leave me with bruises. I need to know ahead of time what they need from me and where it’s happening. Who is the research staff?”

Time and competing demands

“There are many reasons why African Americans don’t do studies, because they have problems. They may have home issues. Where do they have the time to do that? And when your plate is full, you don’t need to go to another study and sit down and listen. I already get blood draws at my doctor’s office.”

Transportation

“They can pick me up and take me; I’ll put in the time for the study and let them collect my samples.”

Facilitators of acceptance

Incentives

“Like I said, incentives help. [Investigators] have everything. They have coffee, food, and other stuff.”

Altruism

“They take a pint. I don’t care what they do with it. I’m hoping it’s going to help somebody.”

Family

“My brother...he died of cancer. I want to know everything [that’s] wrong with me. That’s why I decide to participate in research. Even if the research involves needles and biomarkers.”

Perceived benefits

“They can collect it [biomarkers] because there are many problems that can be solved with research.”

care and researchers collecting biological specimens, African American participants recommended that investigators build rapport and trust with community through church and other community groups and leaders and select community-prioritized research topics. Latino and African American interview and focus group participants believed that interest in research participation would increase if biomarkers were directly related to the health priorities of the community.

Facilitators of Acceptance

Participants mentioned interest in their personal health, altruism, and direct benefits (eg, incentives) as reasons that they would accept biomarker collection and storage. Financial/material incentives were very important in the decision to participate in biomarker research. Older Latino and African Americans identified monetary compensation for their time, food and drinks, and gift cards as being most persuasive. One participant stated that “*Make sure you have some exchange, money is good, and breakfast works also.*” They believed that it was appropriate and fair to receive an incentive in exchange for their time and participation. Altruism was the most common subtheme mentioned in this domain (Table 4).

DISCUSSION

This exploratory study of older Latino and African American adults provides important information about potential strategies to improve their acceptance of the use of biomarkers in research. We identified key issues about

and engagement of community leaders. Table 3 lists illustrative quotes about facilitators of opportunity. Participants wanted study personnel to follow universal precautions when they collect bio-specimens. They wanted to take consent forms home and review them with their family and doctors. On participant said, “*I would want to get the package in advance, so that way you can read the detail of what it’s going to be about.*”

Participants wanted more thought into the presentation of biomarkers and suggested the use of multimedia and visual aids by investigators during the recruitment process. One participant said, “*I would have charts. I would have filmstrips. Sometimes when people read they have a tendency to forget what they read...so a video and putting it together nicely and making sure it’s understandable, that would be best.*”

To mitigate the mistrust of health

the collection and storage of biomarkers that investigators may find useful when developing research recruitment and retention protocols. As expected, our results identified mistrust of staff with the collection of biomarkers and with the storage of biomarkers by investigators, in addition to several previously unidentified barriers such as fear of harm and collection burden. More importantly, our results also identify potential solutions and may help us understand potential ways to

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mitigate the mistrust about biomarkers in this underserved population of older adults. We describe several useful participant-driven facilitators to acceptance of biomarkers in research.

This study expands the literature by focusing on Latinos, African Americans and biological markers of health. Some of the themes in this study were similar to that reported in a qualitative study by Hiratsuka et al about bio-banking research in native

people.³⁰ However, the majority of published research in this area pertains to recruitment/retention of minorities to cancer clinical trials.¹⁷ A published review of the literature identified 65 studies on barriers to recruiting underrepresented populations to cancer trials, but only a few included Latinos.¹⁷ Other relevant studies of ethnic minorities focus on participation in general clinical research^{8,16,25} and also found that mistrust of health care is a barrier to participating in clinical research.¹⁶ We expand on what has been published about mistrust to include new problems and potential solutions specific to perceptions of biomarker collection and storage.

Participation in biomarker research could be increased among African American and Latino older adults by partnering with trusted community groups (eg, faith-based), culturally tailoring recruitment/educational materials, hiring staff from the community to collect the biomarkers, and being explicitly clear about the processes involved with the collection and storage of biomarkers. Our data also suggest that different modes of recruitment/educational materials (e.g, videos) are important to enhance the acceptance of biomarkers. For Spanish-speaking Latinos, acceptance of biomarkers could be improved by using recruitment/education materials that are translated correctly and are sensitive to language differences between Latino subgroups.

This study has limitations in that our sample consisted of a small convenience sample of community-dwelling minority older adults that may limit the generalizability of our findings. We recruited participants from

California and our results may not be generalizable to other geographic areas or all Latino or African American subgroups. We did not include Latinos whose primary language was English and the majority of participants were female. Although we used standard qualitative methods in this study, the interpretation of the qualitative transcripts are subject to bias from investigators. We potentially minimized bias by having investigators independently review the transcripts and having any discrepancies adjudicated by a third investigator. Members of the aging community also read the transcripts and provided their opinions and interpretations of the data.

Investigators may find our results useful to increase minority senior participation in research studies that require collection and/or storage of biomarkers. Community-level results from this study include strengthening of ongoing collaborations between four NIA-funded centers at UCLA (RCMAR, LA CAPRA, USC/UCLA Biodemography Center, and the UCLA CTSI) to increase community awareness and acceptance of biomarkers. As a next step, we plan to disseminate culturally and linguistically sensitive multimedia and Internet-based educational materials with input from community service providers and older minorities.

In summary, results from this study may help identify best practices and inform community-engaged scholarship to develop culturally sensitive protocols for biomarker collection and storage. The study represents an important step in the adaptation of modified research protocols for ethnic minority older adults.

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