

Elena Portacolone, PhD, MPH, MBA<sup>1</sup>; Nynikka R. Palmer, DrPH, MPH<sup>2</sup>; Peter Lichtenberg, PhD<sup>3</sup>; Catherine M. Waters, PhD, RN<sup>4</sup>; Carl V. Hill, PhD, MPH<sup>5</sup>; Sahru Keiser, MPH<sup>1</sup>; Leah Vest, MBA<sup>1</sup>; Marsha Maloof, MPA<sup>6</sup>; Thi Tran, BA<sup>1</sup>; Paula Martinez, BA<sup>1</sup>; Javier Guerrero, BA<sup>1</sup>; Julene K. Johnson, PhD<sup>1</sup>

Black/African American populations are underrepresented as participants in dementia research. A major barrier to participation of African American older adults in dementia research is a tendency to distrust research institutions owing to both historical and contemporary racism. Building on the Ford framework, the objective of our study was to examine factors that influence participation in dementia research among African American older adults and caregivers, with an emphasis on understanding factors related to trust. Data were collected during January 2019 and March 2020 from 10 focus groups with African American older adults (n=91), 5 focus groups with caregivers (n=44), and interviews with administrators of community-based organizations (n=11), and meetings with our Community Advisory Board. Inductive/deductive content analysis was used to identify themes. The results identified an overall tension between distrust of researchers and a compelling desire to engage in dementia research. This overarching theme was supported by six themes that provided insights about the multiple layers of distrust, as well as expectations about the appropriate conduct of researchers and academic institutions. Strong commitment to the community was identified as a priority. The findings suggest that a paradigm shift is needed to increase the representation of African Americans in dementia research. In this new paradigm, earning the trust of African American communities becomes a systemic endeavor, with academic, state, and national institutions deeply committed to earning the trust of African American communities and guiding researchers in this endeavor. The findings also generated actionable recommendations to help improve representation of African American older adults in dementia research. *Ethn Dis.* 2020;30(Suppl 2):719-734; doi:10.18865/ed.30.S2.719

After all these years, why this study now? It didn't just happen. Black people always get the worst diseases and go through the worst changes before anybody else. Now, where did this come from, this interest in our well-being?

*Focus group participant*

Trust is everything, and it takes time. It's not easily given.

It's something that is earned.

*Administrator of community-based organization*

## INTRODUCTION

Black/African American populations are underrepresented as participants in dementia research.<sup>1-7</sup> This

is a highly significant public health concern because African Americans are twice as likely as Whites to have Alzheimer's disease and related dementias (ADRD).<sup>8-12</sup> A recent systematic review of 49 randomized controlled trials developed to treat Alzheimer's disease reported that only 59% of studies disclosed participants' race/ethnicity, and only 4.4% of participants were African American or Latino.<sup>4</sup> This underrepresentation reduces the generalizability of research findings and hinders the understanding of disease mechanisms,<sup>3,4,7</sup> further widening health disparities.<sup>13</sup> Given that there are currently 200 clinical trials on dementia with a goal of recruiting >70,000 study participants,<sup>1,14</sup> most of them older adults, there is

**Keywords:** Trust; Caregivers; Focus Groups; African Americans; Dementia; Aged

<sup>1</sup> Institute for Health & Aging; University of California San Francisco, CA

<sup>2</sup> Division of General Internal Medicine at Zuckerberg San Francisco General Hospital, University of California San Francisco, San Francisco, CA

<sup>3</sup> Department of Psychology, Institute of Gerontology, Michigan Center for Urban African American Research, Wayne State University, Detroit, MI

<sup>4</sup> School of Nursing, University of California San Francisco, San Francisco, CA

<sup>5</sup> Alzheimer's Association, Chicago, IL

<sup>6</sup> Maloof & Associates, San Francisco, CA

Address correspondence to Elena Portacolone, PhD, MPH, MBA, Institute for Health & Aging; University of California San Francisco, 3333 California Street, Suite 340, Box 0646, San Francisco, CA 94118; elena.portacolone@ucsf.edu

an urgent need to increase representation of African Americans in clinical research about ADRD to protect public health in the United States.

A major barrier to participation of African American older adults in dementia research is a tendency to distrust research and medical institutions owing to historical and contemporary racism and abuse.<sup>1,15-21</sup> Because earning the trust of potential study participants is essential for considering participation in dementia research, the goal of this study was to gain an in-depth understanding of expectations associated with trust in general, and in specific regard to participation in dementia research among African American communities.

Trustworthiness is defined as “the capacity to commit oneself to fulfilling the legitimate expectations of others.”<sup>22</sup> Thus, knowing the subjective expectations associated with trust, as well as fulfilling such expectations, might increase the likelihood of being trusted. A focus on building trust specifically from the perspectives of African American older adults is one strategy that could help increase participation in clinical research about ADRD.

To earn the trust of African American communities, researchers have often partnered with administrators of community-based organizations (CBOs), including faith-based organizations, which typically are culturally relevant and trusted in their communities. Such community-engaged strategies have had some success recruiting African American older adults for specific studies.<sup>23-29</sup> However, because these

strategies have typically been only ad-hoc, principal-investigator specific, and lacking organization at the institutional (academic) level, very little is known about the specific mechanisms that contribute to developing trust over time toward researchers and academic institutions. Moreover, the construct of trust has seldom been analyzed in depth in recruitment science,<sup>30,31</sup> even though trust toward researchers is usually a key factor in decision-making about research participation. A better understanding of the construct of trust and its related expectations will facilitate the development of structured and scalable approaches to accelerate the engagement of African American older adults in dementia research.

To facilitate the translation of our results into actionable strategies for researchers and academic institutions, we applied the Ford et al (Ford) conceptual framework that identifies barriers and facilitators to enrollment into research.<sup>32,33</sup> Initially developed to accelerate the recruitment of underrepresented populations in cancer research, this framework identifies three factors related to increasing representation of diverse individuals in research. The first factor is Awareness, which focuses on general knowledge about a study (eg, knowing about the study, knowing that someone may qualify, having a general understanding about research). The second factor is Opportunity, which focuses on having access to research procedures (eg, having financial resources and the time to travel to study visits). The final factor is

Acceptance, which focuses on the process of decision-making (eg, deciding to participate after weighing risks and benefits). This factor, in particular, is linked to trust because a decision to participate in research requires that participants trust the study and the research team.

Building on prior work done with the Ford framework,<sup>32,34</sup> the objective of our study was to examine factors that influence participation in dementia research among African American older adults and caregivers of African American older adults with dementia, with an emphasis on understanding factors related to trust. Because distrust is a major barrier to research participation,<sup>35-42</sup> we examined expectations associated with trust overall, as well as expectations associated with trust toward researchers and CBOs. The ultimate goal of our study was to provide actionable strategies to increase representation of African American older adults in dementia research.

## METHODS

### Study Design

We used qualitative methods with focus groups and interviews as the primary mode of data collection to identify factors that influence participation in dementia research among African American older adults and caregivers. To better understand our findings, we supplemented data from focus groups with interviews with administrators of CBOs that were identified as trusted by focus group participants. Finally, to add further depth to the

analysis, we presented our findings to our Community Advisory Board (CAB) of African American stakeholders to elicit their perspectives. This iterative process allowed us to validate and expand our preliminary findings by comparing and contrasting the perspectives of four stakeholder groups: African American older adults, caregivers, CBO administrators, and CAB members.

### Study Participants

We recruited three stakeholder groups with purposive sampling. Inclusion criteria for older adults included being aged >50 years and self-reporting as Black or African American. Inclusion criteria for caregivers included being aged >18 years, and being a family member or friend who had primary responsibility for providing or coordinating care without financial compensation<sup>43</sup> to at least one African American individual with diagnosed or undiagnosed cognitive impairment over the last year. The inclusion criterion for CBO administrators was working as an administrator in an organization that was identified as being trusted by focus group participants.

### Recruitment

We recruited participants in two ways. First, we recruited African American older adults and caregivers through the support of local CBOs serving primarily African American communities in two sites with a high representation ( $\geq 25\%$ ) of African American residents: Detroit, MI, and the San Francisco Bay Area, CA. Local CBOs assisted with recruitment. In particular, the re-

search project managers in each site provided recruitment flyers, and the CBO administrators solicited participation to their clients by endorsing our study and sharing recruitment flyers showing university logos and the name and address of their CBO. Second, we recruited CBO administrators from CBOs that focus group participants said that they trusted.

### Data Collection

Data were collected from focus groups, interviews, CAB meetings, and interviews with CAB members. As preliminary activities to refine questions and procedures, we organized two mock focus groups and interviewed six African American older adults. Data collection then started in January 2019 and ended in March 2020. The Committee of Human Research of the University of California, San Francisco approved the study (approval number 17-23278).

#### *Focus Groups Methods*

The overall goal of the focus groups was to understand, in depth, participants' expectations associated to trust overall, as well as trust toward specific CBOs and researchers. Focus groups were: facilitated by African American researchers; designed to last about 90 minutes; and audio recorded and professionally transcribed. Focus groups were held in local community centers and CBO facilities. Participants received a \$20 gift card for their time and participation. In each focus group, facilitators shared statistics on the low participation of African American communities in dementia research and explained one reason why it is impor-

tant to increase the number of study participants in dementia research (eg, it is impossible for researchers to understand the reason why dementia is more prevalent in African American populations if most study participants are White). They added that the first step is to learn from the community about their perspective. To elicit perspectives on overall trust, facilitators asked the same question: "What makes you trust someone?" These unstructured reflections on trust were followed by questions that asked participants to identify CBOs that they trusted and to explain the reasons that make them trust specific CBOs. Participants were then asked whether an invitation from specific CBOs would lead them to consider participating in research, and whether other factors had to be weighed before doing so, and why. Finally, facilitators asked about ways by which researchers and CBO administrators could work together to increase the representation of African American communities in dementia research.

#### *Interviews Methods*

To supplement findings from the focus groups, administrators of CBOs that were indicated as trusted by older adults and caregivers were interviewed in person. Using an interview guide designed to last for 60 minutes to limit participant burden, we elicited administrators' perspectives about barriers and facilitators to accelerate the engagement of African American communities into dementia research, with an emphasis on the role of trust. Most interviews were administered by the lead author and were audio recorded

and professionally transcribed. Interviewees received a \$20 gift card for their time and participation.

### *Eliciting CAB's Feedback*

The project manager and the lead author presented the preliminary findings in person to the CAB with the goal of eliciting their overall reaction. The six members of the CAB (2 men and 4 women; all African American) included an administrator of dementia services, an administrator of city aging services, a county public health officer, a publisher, a clergy, and a leader of an African American non-profit organization. Two were previously involved in prior research projects. After the meeting, we gave them the option of reviewing an earlier version of this manuscript. One CAB member agreed to review the manuscript in detail, and she was then interviewed over the phone by the lead author to gather her detailed feedback. CAB members received an honorarium of \$100 per hour.

### **Analysis**

Transcripts of focus groups and interviews were entered into Atlas.ti software for data analysis. Transcripts were then analyzed with inductive and deductive qualitative content analysis,<sup>44</sup> a commonly used method of qualitative data analysis.<sup>45-47</sup> Three independent coders analyzed the transcripts. One coder had not been involved previously in the study. Transcripts were analyzed line by line,<sup>48-50</sup> to understand what factors might influence the decision to participate, or not in dementia research. The deductive analysis was guided

by the Ford framework<sup>32,33</sup> whereby coders identified barriers and facilitators for each factor of the model, paying particular attention to the construct of trust. The framework was useful to organize our analysis because its wide scope allowed us to examine the perspective of different stakeholders' groups. The inductive portion of analyses ensured that the coders captured unexpected themes such as the generalized distrust and the desire for health-related information and engagement. The lead author identified these themes through making connections among codes, writing memos, and having iterative discussions with coders, facilitators, and the project manager. The overarching theme was identified by making connections among themes, as with prior research.<sup>51</sup> In the first stage of analysis, we focused on identifying themes and subthemes. In the second stage of analysis, we compared and contrasted narratives from each stakeholder group to assess whether they corroborated, negated, or expanded on one another, which adds depth and rigor to the analysis.

### **Data Validation**

For rigor, reproducibility, and transparency, we used four approaches to validate the data. First, during data collection, we searched for disconfirming evidence.<sup>52</sup> This standard technique in qualitative research allows researchers to test the strength of observed patterns. Second, we triangulated data from stakeholders groups across sites, paying particular attention to discrepancies in the data.<sup>53,54</sup> Third, collaborative coding was used dur-

ing data analysis. Three independent coders coded the data, and the researchers who conducted the interview did not code the corresponding transcript. Finally, we used the Consolidated Framework for Reporting Qualitative Research (COREQ).<sup>55</sup> Developed to promote explicit and comprehensive reporting of qualitative studies, this framework enhances validity because it provides 32 items that researchers need to consider when conducting qualitative research.

## **RESULTS**

We conducted 15 focus groups: 10 with African American older adults (n=91) and 5 with caregivers (n=44) of African American older adults with cognitive impairment. Focus group participants were mostly African American (92%) and women (80%) with a range of education levels. We also interviewed 11 CBO administrators. Table 1 details participants' characteristics.

The overarching theme that emerged from the data was identification of a tension between distrust toward researchers/institutions and the compelling desire to engage in dementia research. In addition, six themes and related sub-themes were identified.

### **A "Wall" of Distrust**

Opening questions about trust ("What makes you trust someone?") often led to spontaneous and unprompted accounts of distrust, with participants explaining their unease with trusting others.

**Table 1. Participant characteristics**

	Older adults	Caregivers	Administrators of community-based organizations	Total
Total # of participants	91	44	11	146
Age, mean, (range)	69 years (51 - 93)	66 years (37 - 87)	60 years (38-76)	65 years (37-93)
Sex, Female	72 (79%)	35 (80%)	9 (82%)	116 (79%)
Race/ethnicity				
Non-Latino African American	82 (90%)	42 (95%)	10 (91%)	134 (92%)
Hispanic or Latino	3 (3%)	1 (2%)	0	4 (3%)
More than one race	5 (5%)	0	0	5 (3%)
Not provided/other	1 (1%)	1 (2%)	0	2 (1%)
Education				
≤High school	9 (10%)	3 (7%)	0	12 (8%)
High school graduate	11 (12%)	6 (14%)	0	17 (11%)
Some college	21 (23%)	8 (18%)	0	29 (20%)
College graduate	36 (40%)	15 (34%)	1 (9%)	52 (36%)
Graduate degree	14 (15%)	9 (20%)	9 (82%)	32 (22%)
Not provided	0	3 (7%)	1 (9%)	4 (3%)

*“I am very distrustful of everything and everybody,”* explained an older adult.

A caregiver reflected:

*“Because they [beloved ones with dementia] are so vulnerable, you don’t really want nobody around them. You don’t really trust nobody with them. You are scared.”*

The narratives were similar among older adults and caregivers, as well as CBO administrators. Building blocks of this generalized unease were long-standing experiences of disrespect and discrimination. A participant explained that trusting for him was like being open to vulnerability; and because of the abuse that he witnessed over the years, it was hard for him to trust.

This generalized distrust mani-

festated on multiple levels. For example, the government and corporations were often distrusted because of the long-standing legacy of discrimination against the African American community. One CBO administrator reflected:

*“People do not trust the systems because the systems have been oppressive for years and years and years.”*

At an institutional level, academic researchers were often distrusted because they usually did not take enough time to properly explain their procedures and they rarely shared their findings.

*“Once they found out the information about my hair follicle, I would be the last person that they would help,”* said an older adult.

Participants also were wary that their information and accounts would be used against them. Specifically, participants worried that the information that they provided could be used to perpetuate negative stereotypes — for example, a participant asked her son to dismiss a survey:

*“They’re going to say you’re from a single parent Black family. No father in the home, so this is what we expect of you. By the time you are 25, you will be in jail, on drugs, house full of babies, or dead.”*

The reasons for conducting this study, as well as other studies, were questioned. Participants often wondered about the motivations underlying the research. In particular, they were concerned that the researchers were mostly driven by profit and career advancements.

Spontaneous references to Tuskegee and Henrietta Lacks abounded.

*“I know it was a long time ago,”* a CBO administrator noted, and added, *“But that trust has never been regained or gained.”*

Community members were also sometimes distrusted. Participants were particularly concerned about local organizations claiming to support their communities but having poor follow-throughs. A caregiver said,

*“I don’t trust people as far as professionals go, because they have a different agenda.”*

A few participants questioned the motives of pastors and physicians. In general participants agreed that having a professional title (eg, professor, doctor) was not enough to foster trust. Finally, at the micro level, despite some accounts of participants who made an effort to trust acquaintances as a default, a few participants said that they distrusted their spouses or family members, suggesting that trusting others was a major effort. Taken together, the findings point to the existence of a multilevel wall of distrust as a major barrier to all types of engagement in research, including dementia research.

### Expectations Associated with Trust

After acknowledging accounts of distrust, facilitators elicited expectations associated with trusting someone, which included people in

their personal life as well as professionals. Overall, having someone’s best interest at heart led to trust.

*“I think trust is a form of love,”* an older adult reflected.

Most participants explained that they trusted people who showed evidence of integrity:

*“Just be really honest with people,”* one CBO administrator suggested.

Being “loving, “caring,” “kind,” “heartfelt” usually led to trust. A caregiver explained:

*“I got to feel they have heart. If they got heart and I feel that they are to be good to me ..., then I can trust them.”*

Participants often placed particular attention on whether they felt “comfortable” while interacting with

---

*“I think trust is a form of love,” an older adult reflected.*

---

someone, paying attention to their intuition. At a practical level, trustworthy people were expected to consistently act according to their word; they were dependable and “walked the walk.” Type of actions also mattered. Providing practical help usually led to trust. Examples of help includ-

ed checking regularly on one’s health, giving toys to children who were victim of violence, and help with paying bills. Providing helpful and truthful information led to trust as well. Examples ranged from information on low-interest mortgages to better understanding of cholesterol levels. Follow-ups and going the extra mile were particularly valued. A caregiver said:

*“I expect follow through on promises and commitments.”*

Additionally, to trust someone, it was important to know them for a long time because it was an opportunity to observe the consistency of their behaviors. A caregiver reflected,

*“By the amount of time I know them, I can pretty much tell what kind of person they are.”*

Finally, trust could be transferred onto others. Participants explained that they could trust someone who was introduced by a trustworthy person or organization. For example, in one focus group, caregivers explained that they decided to participate in our study only because they were invited by a trusted CBO administrator. One participant of that group also specified,

*“I’ll come back as long as [administrator of trusted CBO] is hosting it.”*

If the invitation only came from the academic institution, most of them would not have attended, which leads to the next theme.

### Referral by Trusted CBOs Increases Trust in Academic Researchers

CBO administrators explained that, to recruit participants into dementia research, “trust is everything.” When systematically asked whether they would participate in generic “studies on dementia,” older adults and caregivers were usually hesitant. Caregivers were particularly protective of their loved ones. For example, reflecting on dementia research, one caregiver asked,

*“If you’re touching my mom, can I be in the room? I want to see everything you’re doing.”*

However, when asked whether they would consider participating in studies endorsed by administrators of trusted CBOs or trusted professionals (eg, physicians, nurses, nuns, pastors), older adults and caregivers were more open to considering participation. A few participants even said that such referrals would have been enough to persuade them to participate. An older adult said,

*“I am already willing [to participating in a dementia study] just hearing the [CBO] name.”*

In general, participants explained that, while a referral from someone trusted made them more inclined to participate, they still needed to have a good understanding of the “whole picture.” Some participants specified that they would be more inclined to consider the referral if the trusted CBO had some expertise broadly related to the study (eg, health, old age,

dementia). Participants also agreed that the referral of multiple trusted CBOs would increase their likelihood of participating in dementia research. One caregiver reflected,

*“I think it needs to be a collaboration of maybe more than two or even three organizations to push past that [wall of distrust].”*

According to one CBO administrator, this openness to participation was rooted in the community’s assumption that trusted CBOs carefully evaluated the proposed study before endorsing it. Another CBO administrator explained that it was hard for her to endorse studies because the reputation of her organization might be tarnished if these studies reveal themselves to be harmful to participants.

### Expectations Associated with Trusting Academic Researchers

To earn the trust of African American communities, researchers need to show their tangible investment in furthering the wellbeing of these communities, and they need to be transparent. In particular, most participants explained that, to increase trust of researchers and their institutions, it would be beneficial to interact with racially/ethnically concordant researchers, ie, “someone who looks like me.” African American researchers should be a critical component of research teams. One caregiver explained,

*“I want to look for people [researchers] of color with hopes*

*that they’re going to have more concern because they’re going to see there’s potentially their grandmother, their mother.”*

In addition, participants often emphasized that researchers must find the time and the way to patiently “break down” the information about their research study, with patience and clarity, so that the details and overall purpose of the study are understandable and transparent.

*“You would have to give me all the details,”* an older adult said.

A caregiver echoed,

*“I got to read the whole consent form and find out exactly what you’re doing.”*

It is important that researchers explain, in detail, what participants will undergo and why. Researchers also must take the time to explain the purpose of the project in “simple language.”

Participants further explained that they must understand how their information will be used and how confidentiality will be ensured.

*“The privacy for me is the big issue,”* a caregiver noted.

As altruism was a key motivator to participating in research, participants wanted to understand how participating in specific studies would help others. For example, during our focus groups, participants often were interested to learn that African

American adults are twice as likely as White adults to develop dementia, which made them realize that participating in dementia research was important to prevent dementia in African American communities.

Finally, participants added that the flow of information from researchers to participants and their communities must be consistent and deeply interwoven. “*Don’t study [my beloved one] and just walk away with what you found out,*” a caregiver said. Specifically, researchers should keep these communities abreast of their activities and findings throughout the process. An older adult explained, “*If you bring it [the findings] to us, then we can be educated on what we need to know for our Black communities.*” Participants encouraged researchers to organize discussion groups like our focus groups to discuss future research projects before submission to funding agencies. Communications should continue during recruitment and dissemination of the findings. Researchers should not only explain their findings, but also think of ways the findings can support local community issues. A CBO administrator suggested to use as a reference the ongoing Black Women’s Health Study at Boston University<sup>56,57</sup> because of its commitment to improve the health of African American women and its consistent dissemination of findings to participants and African American communities.

### **Desire for Health-related Information and Engagement**

Participants expressed a strong desire to acquire new knowledge

about dementia and other topics. An older adult explained,

*“[Researchers should] explain what the concept is of dementia, because a lot of people don’t know.”*

Another participant added,

*“The only way that we’re going to move forward and elevate ourselves is to have a better understanding.”*

Participants often expressed their concerns about not knowing whether they or their loved ones had dementia:

*“I’m afraid that I might have inherited it. When I forget something it really upsets me,”* an older adult said.

Talking about dementia was often perceived as a “taboo.” For example, an older adult explained,

*“Usually people don’t want to talk about their members having Alzheimer’s or dementia. It’s almost like it’s a forbidden thing.”*

She then stressed the importance of learning about larger trends in the epidemiology of dementia:

*“We come to grips of recognizing ...that it’s wider spread than we want to acknowledge.”*

Participants also longed for more information on how to navi-

gate dementia services, pointing out that public services only served a fraction of all people with dementia. Information on healthy behaviors was also sought after, as well as information on how to access housing. In general, participants enjoyed participating in the discussions, voicing their concerns, exchanging perspectives, and getting to know each other, as well as the members of our research team, all women of color. At the end of a focus group, one caregiver said,

*“If you can do more of these coming together...This has really educated me.”*

Another caregiver echoed:

*“We need to be involved more and we need to be studied more.”*

Facilitators also observed that participants stayed in the room after the end of discussion, eager to talk more about the topics, thus displaying a strong interest in being involved and contributing their unique perspectives.

### **Commitment to the Community Must Come First**

As described in the methods, we took the above findings to our CAB and asked them to review. After our presentation of the findings, members of the CAB expressed their unease about our initial framing of the results. In particular, CAB members were uncomfortable with our attention on supporting researchers in order to ultimately support African



American communities. Instead, the CAB invited us to commit to African American communities first in order to ultimately support the scientific community. The CAB expressed that this perspective is critical because of the limited support that African American communities have historically received from academia, compounded with a legacy of systematic discrimination. Reflecting on research conducted in African American communities, a CAB member asked,

*“Do you [as researchers] meet the expectations associated with trust? Historical data would suggest, not so.”* She added, *“Our stories are not for sale to the highest bidder.”*

To earn trust that was broken many times, the research community must provide strong evidence of a *“serious investment”* in African American communities. The first step is to self-reflect and *“listen beyond listening,”* a mode in which researchers deeply listen to the voices of the community in order to understand their perspectives. In this receptive mode, learning takes over the development of interventions. A CAB member explained,

*“Going with ears open, eyes ready to receive and mouths closed and not fixed on solutions, will provide the greatest rewards.”*

Thus, the return to our community advisors was critical in both interpreting and framing our research.

## DISCUSSION

The results of this study identified an overall tension between distrust of researchers and academic institutions and a compelling desire to engage in dementia research. This overarching theme was supported by six themes that provided additional insights about the multiple layers of distrust and expectations about how researchers and academic institutions can earn the trust of African American communities to increase representation of African American participants in dementia research. Strong and transparent commitment to the community was identified as a critical priority, and collaborations with trusted CBOs could help facilitate the building of trust and assuring that researchers and academic institutions understand the necessary commitments. A unique aspect of our study was the involvement of multiple stakeholders representing different interests, educational levels, and geographies, including a CAB that provided a transformative reframing of the results. While the involvement of CABs in research is not new, our study identified the central value of the CAB in integrating perspectives from multiple stakeholders into actionable steps and the need for a paradigm shift in recruitment science, particularly related to dementia research.<sup>58</sup>

Similar to other studies,<sup>35-42</sup> our study found that distrust is a major barrier affecting participation among African American adults in dementia research. Specifically, our study corroborates the findings of other studies on recruitment of African American

communities,<sup>16,30,59</sup> vaccination<sup>60-62</sup> and health care utilization<sup>63-65</sup> that have investigated, in-depth, the construct of distrust in African American communities. Interestingly, some participants' quotes in other studies are almost identical to ours, eg,

*“It is because of the history of the medical industry and its distrust on how they treated African Americans... I haven't seen where they have tried to build the trust.”*<sup>60</sup>

---

*A unique finding from our study is an emphasis on an untapped desire of African American communities to be engaged in dementia research.*

---

The construct of historical trauma, defined as a *“cumulative and psychological wounding over the life span and across generations emanating from massive group trauma experiences,”*<sup>66</sup> is sometimes used to provide insights into the suffering that stems from decades of racism and discrimination toward African American communities. In the context of research, multiple harmful experiences associated with research studies perpetuate the cumulative

**Table 2. Actionable recommendations for researchers and academic institutions to facilitate representation of African American older adults in dementia research based on the Ford framework<sup>32,34</sup> (Part 1 of 2: Awareness)**

Factors	Recommendations for researchers and academic institutions	Theme(s) that inspired the recommendation
Awareness	Be aware of the challenges that African American communities have had to contend with at a local and national level	A wall of distrust Commitment to the community must come first
	Be aware of the specific priorities and concerns of the African American residents of studies sites. Identify as much as possible ways by which the activities of researchers and their institutions can address, at least partially, these concerns.	Commitment to the community must come first
	Take the time to clearly explain protocols and purpose of their study. Embed these procedures in study protocols.	Expectations associated with trusting academic researchers
	Leverage any opportunity to timely disseminate findings through local educational presentations, flyers, and social media.	Expectations associated with trusting academic researchers Desire for health-related information and engagement Commitment to the community must come first
	Identify educational topics that are pressing to African American residents in specific sites.	Desire for health-related information and engagement Commitment to the community must come first

trauma associated with research participation. In fact, institutional review boards and informed consent procedures for the protection of human research participants, among other strategies, were created to address these research injustices. However, further work is needed to earn the trust of historically marginalized communities.

Findings from our study also provided insights into the concept of trust. Trust is a “voluntary action based on expectations of how others will behave in relation to yourself in the future,” explains Gilson,<sup>67</sup> to the point that trusting is comparable to a leap of faith.<sup>68</sup> Thus, trust involves uncertainty because it is unknown how others will behave. The higher the uncertainty, the harder it is to trust, and the more vulnerable we feel if we do trust, as our participants explained. For African American

communities, abuse, discrimination, and cultural insensitivity from researchers and academic institutions have heightened this uncertainty.<sup>65</sup> This, in turn, makes African American communities wary of engaging in research,<sup>15,21,69-71</sup> as well as taking vaccines,<sup>60-62</sup> receiving antiretroviral therapy,<sup>72</sup> or considering kidney transplants.<sup>73,74</sup> To make matters worse, broader systemic issues are cast in the background, including limited access to health care<sup>75</sup> and timely dementia diagnoses<sup>3</sup> for African Americans, high costs,<sup>76</sup> and bias on behalf of medical providers (specifically in the area of who is eligible for transplantation),<sup>77</sup> which creates and sustains health disparities.

In our study, African American older adults and caregivers of persons with dementia provided concrete expectations needed to gain trust of their communities. Expectations as-

sociated with trust included being caring, reliable, useful, and known for a long time. These expectations also have been documented in other studies.<sup>31,78</sup> For example, a study of African American men found that trust in health care providers depended on sharing of information, active listening, length of relationship, and expertise.<sup>79</sup> A study of African American parents noted that their trust of their child’s primary care physicians was positively associated with physicians who created partnerships with them.<sup>80</sup> The use of easy-to-comprehend research materials and consistency of involvement in and support of the community were also identified as expectations for gaining trust of African American older adults in the context of research. Another expectation was that African American people should be integral members of research teams and be leaders of

**Table 3. Actionable recommendations for researchers and academic institutions to facilitate representation of African American older adults in dementia research based on the Ford framework<sup>32,34</sup> (Part 2 of 2: Opportunity and Acceptance)**

Factors	Recommendations for researchers and academic institutions	Theme(s) that inspired the recommendation
<b>Opportunity</b>	Organize discussions in African American communities in order to design studies aligned with their priorities and concerns	Expectation associated with trusting academic researchers Desire for health-related information and engagement Commitment to the community must come first
	Provide educational sessions on topic that are relevant to community members, either alone or in partnership with administrators of trusted CBO	Desire for health-related information and engagement Commitment to the community must come first
<b>Acceptance</b>	Be aware of specific expectations associated with trust in African American communities (ie, being honest, dependable, helpful, caring, known for a long time)	Expectations associated with trust
	Self-reflect on past studies (eg, in prior research, did you meet the expectations associated with trust?)	Expectations associated with trust Expectations associated with trusting academic researchers
	Have African American researchers leading the study in multiple roles and being key decision-makers	Expectations associated with trusting academic researchers Commitment to the community must come first
	Design studies specifically aimed at furthering African American's health	Expectations associated with trusting academic researchers Commitment to the community must come first
	Find ways to leverage findings to support local issues	Commitment to the community must come first
	Identify community-based organizations (CBOs) that are deeply trusted	Referral by trusted CBOs increases trust in academic researchers
	Involve administrators of trusted CBOs as team members or consultants	Referral by trusted CBOs increases trust in academic researchers
Ensure that involved administrators of trusted CBOs understand the protocols, requirements, and purposes of research studies	Referral by trusted CBOs increases trust in academic researchers	

the science. Targeted attention on this expectation is needed given recent data documenting that African American researchers remain underrepresented in academic research institutions<sup>81</sup> and receive significantly lower research funding from the National Institutes of Health compared with White counterparts.<sup>82</sup>

A unique finding from our study is an emphasis on an untapped desire of African American communities to be engaged in dementia research. “*We have so much to offer,*” a CAB member noted. All stakeholder groups in our study shared that they want to be involved in

the whole process, from the planning stages to dissemination of the findings. The findings also indicated the conditions needed to facilitate this engagement: researchers and academic institutions need to be invested in the health and wellbeing of African American communities; research teams need to include African American researchers and be led by African American researchers; researchers need to adopt trustworthy behaviors; and increase information exchange between the academia and African American communities.

Taken together, the findings from our study and mounting evi-

dence from other studies<sup>1,7,35,60,64</sup> suggest that a paradigm shift is needed to increase the representation of African American older adults in dementia research. This shift involves expanding the efforts of individual researchers involved in recruitment to engaging academic research institutions in a more systematic and coordinated way. In particular, research institutions need a more intentional commitment to improving the health and well-being of local communities. Specifically, researchers should work collaboratively with African American communities, by gaug-

ing their perspectives and working in tandem toward solutions. Thus, commitment to the community needs to come first. This shift is needed because the distrust toward researchers and research institutions is so deeply rooted that a coordinated and systematic effort is needed. Importantly, a commitment to prioritize the health of African American communities, as well as to make amends for the legacy of racism and mistreatment in research, can only be accomplished at a systemic level rather than at the level of individual researchers. For example, the Healthier Black Elders Center was established at Wayne State University to engage African American communities in research through education, exercise classes, concerts, and social events.<sup>83</sup> As another example, anchor institution strategies are increasingly being used by universities and other government agencies to improve the health and social welfare of local communities and ultimately advance health equity.<sup>84,85</sup> It is likely that systemic strategies like this will have the added benefit of improving trust and, thereby, improving engagement of minority communities in health research overall. The city of San Francisco and the University of California, San Francisco, for example, recently convened an Anchor Institution Task Force.<sup>86</sup> In addition, the National Institutes of Health and other government agencies should consider supporting institutions in key Black American communities that monitor and evaluate engagement among researchers to provide assurance, a key aspect of public health.

### **Recommendations to Improve African American Representation in Dementia Research**

Guided by the Ford framework,<sup>32,33</sup> the findings from our study also generated preliminary actionable recommendations for researchers and academic institutions to help improve representation of African American older adults in dementia research (Tables 2, 3). These recommendations in three domains, awareness, opportunity, and acceptance, are particularly useful to research teams who are led by non-African American principal investigators who are invested in addressing unmet needs of African American communities in dementia research.

#### *Awareness*

Participants in our study emphasized expectations associated with trusting researchers and academic institutions. For example, participants recommended that researchers be aware of current and historical challenges experienced by African American communities. They also recommended that researchers clearly explain the purpose and procedures associated with a study to help improve transparency. Other recommendations are listed in Tables 2, 3.

#### *Opportunity*

The findings from our study suggested that African American communities want to be involved in all stages of research. For example, participants recommended organizing discussions about research design and how the research addresses the health and wellbeing of African American

communities. Participants also suggested that researchers could deliver educational topics that interest local communities (eg, managing cholesterol, obtaining low-interest loans).

#### *Acceptance*

Participants in our study recommended that researchers be aware of expectations associated with trust, including having African American researchers function as leaders for studies and ensuring input from trusted community organizations. African American stakeholders must be involved in decision-making because the ability to influence the course of events reduces uncertainty, which in turn fosters trust.<sup>67</sup> Importantly, studies need to be designed so that they improve the health and wellbeing of African American communities. While many of the recommendations apply to individual researchers, the findings also suggested that a more systematic approach to standardizing these recommendations, which can only happen on university, state, and national levels to provide assurance.

### **Limitations**

There are several limitations to our study. Having only two sites and a limited sample of CBO administrators limits the generalizability of our findings. The fact that our sample included predominantly women also limits generalizability. Additional strategies to increase gender diversity, including the perspective of men, are needed. For example, recruitment channels could include outreach to organizations where men are over-represented, such as frater-

nities and barbershops. Another limitation is that we did not organize focus groups with African American adults aged <50 years who may have different perspectives on dementia research. For example, one study on vaccinations<sup>60</sup> suggested that younger generations are more trusting of research than older generations, which warrants further investigations.

## CONCLUSION

In summary, the findings from our research involving multiple stakeholder groups, including a CAB who helped transform our results, indicate that, in order to increase representation of African American older adults in dementia research, a commitment to the health of a community must come first. In addition, addressing issues related to distrust and trust should be central to creating strategies that aim to increase representation of African American participants in dementia research. In particular, academic institutions must earn and keep the trust of African American communities in order to increase representation of African American participants in dementia research, and ultimately to eliminate health disparities. Interdisciplinary collaborations with stakeholders from diverse racial/ethnic backgrounds and organizations are critical, using the words of a CAB member, to “*help the history elevate itself.*” In this new paradigm, earning the trust of African American communities becomes a systemic endeavor, with academic, state, and national institutions deeply com-

mitted to earning the trust of African American communities and guiding researchers in this endeavor.

### ACKNOWLEDGMENTS

The author(s) disclose receipt of the following financial support for the research, authorship, and/or publication of this article. This work was supported in part by National Institutes of Health/National Institute for Aging (NIH/NIA) grant 2R13AG023033-16 and NIH/NIA (K01AG049102 PI Portacolone, R03 AG060354 PI Portacolone). This work was also supported by the Alzheimer’s Association (2018-AARG-589788 PI Portacolone). The Michigan Center for Urban African American Research at Wayne State University (P30 AG015281) and the Center for Aging in Diverse Communities at the University of California San Francisco (P30 AG15272) also supported this work. No funding source had any role in the study design; collection, analysis, or interpretation of data; writing of the report; or the decision to submit the article for publication. The content is solely the responsibility of the authors and does not necessarily represent the official views of the National Institutes of Health, the Alzheimer’s Association, Wayne State University, or the University of California.

### CONFLICT OF INTEREST

No conflicts of interest to report.

### AUTHOR CONTRIBUTIONS

Research concept and design: Portacolone, Johnson, Lichtenberg; Acquisition of data: Portacolone, Keiser, Vest, Maloof; Data analysis and interpretation: Portacolone, Johnson, Palmer, Keiser, Tran, Martinez, Guerrero; Manuscript draft: Portacolone, Johnson, Palmer, Lichtenberg, Waters, Hill, Keiser, Vest, Maloof, Tran, Martinez, Guerrero; Acquisition of funding: Portacolone, Johnson, Lichtenberg; Administrative: Keiser; Supervision: Portacolone, Johnson, Lichtenberg, Keiser

### REFERENCES

1. Watson JL, Ryan L, Silverberg N, Cahan V, Bernard MA. Obstacles and opportunities in Alzheimer’s clinical trial recruitment. *Health Aff (Millwood)*. 2014;33(4):574-579. <https://doi.org/10.1377/hlthaff.2013.1314> PMID:24711317
2. Fargo KN, Carrillo MC, Weiner MW, Potter WZ, Khachaturian Z. The crisis in recruitment for clinical trials in Alzheimer’s

and dementia: an action plan for solutions. *Alzheimers Dement*. 2016;12(11):1113-1115. <https://doi.org/10.1016/j.jalz.2016.10.001> PMID:27836052

3. Barnes LL, Bennett DA. Alzheimer’s disease in African Americans: risk factors and challenges for the future. *Health Aff (Millwood)*. 2014;33(4):580-586. <https://doi.org/10.1377/hlthaff.2013.1353> PMID:24711318
4. Canevelli M, Bruno G, Grande G, et al. Race reporting and disparities in clinical trials on Alzheimer’s disease: A systematic review. *Neurosci Biobehav Rev*. 2019;101:122-128. <https://doi.org/10.1016/j.neubiorev.2019.03.020> PMID:30946856
5. Babulal GM, Quiroz YT, Albenis BC, et al; International Society to Advance Alzheimer’s Research and Treatment, Alzheimer’s Association. Perspectives on ethnic and racial disparities in Alzheimer’s disease and related dementias: update and areas of immediate need. *Alzheimers Dement*. 2019;15(2):292-312. <https://doi.org/10.1016/j.jalz.2018.09.009> PMID:30555031
6. Faison WE, Schultz SK, Aerssens J, et al. Potential ethnic modifiers in the assessment and treatment of Alzheimer’s disease: challenges for the future. *Int Psychogeriatr*. 2007;19(3):539-558. <https://doi.org/10.1017/S104161020700511X> PMID:17451614
7. Shin J, Doraiswamy PM. Underrepresentation of African-Americans in Alzheimer’s Trials: a call for affirmative action. *Front Aging Neurosci*. 2016;8:123. <https://doi.org/10.3389/fnagi.2016.00123> PMID:27375473
8. Tang MX, Cross P, Andrews H, et al. Incidence of AD in African-Americans, Caribbean Hispanics, and Caucasians in northern Manhattan. *Neurology*. 2001;56(1):49-56. <https://doi.org/10.1212/WNL.56.1.49> PMID:11148235
9. Potter GG, Plassman BL, Burke JR, et al. Cognitive performance and informant reports in the diagnosis of cognitive impairment and dementia in African Americans and whites. *Alzheimers Dement*. 2009;5(6):445-453. <https://doi.org/10.1016/j.jalz.2009.04.1234> PMID:19896583
10. Gurland BJ, Wilder DE, Lantigua R, et al. Rates of dementia in three ethnoracial groups. *Int J Geriatr Psychiatry*. 1999;14(6):481-493. [https://doi.org/10.1002/\(SICI\)1099-1166\(199906\)14:63.0.CO;2-5](https://doi.org/10.1002/(SICI)1099-1166(199906)14:63.0.CO;2-5) PMID:10398359
11. Chin AL, Negash S, Hamilton R. Diversity and disparity in dementia: the impact of ethnoracial differences in Alzheimer disease. *Alzheimer Dis Assoc Disord*. 2011;25(3):187-195. <https://doi.org/10.1097/WAD.0b013e318211c6c9> PMID:21399486
12. Mayeda ER, Glymour MM, Quesenberry CP, Whitmer RA. Inequalities in dementia incidence between six racial and ethnic groups over 14 years. *Alzheim-*

## Increasing African American Participation in Dementia Research - Portacolone et al

- ers *Dement*. 2016;12(3):216-224. <https://doi.org/10.1016/j.jalz.2015.12.007> PMID:26874595
13. Dilworth-Anderson P, Pierre G, Hilliard TS. Social justice, health disparities, and culture in the care of the elderly. *J Law Med Ethics*. 2012;40(1):26-32. <https://doi.org/10.1111/j.1748-720X.2012.00642.x> PMID:22458459
  14. National Institute on Aging. *Together We Make the Difference: National Strategy for Recruitment and Participation in Alzheimer's and Related Dementias Clinical Research*. Bethesda, MD: National Institute on Aging; 2018.
  15. Tanner A, Kim SH, Friedman DB, Foster C, Bergeron CD. Barriers to medical research participation as perceived by clinical trial investigators: communicating with rural and African American communities. *J Health Commun*. 2015;20(1):88-96. <https://doi.org/10.1080/10810730.2014.908985> PMID:25204763
  16. Hughes TB, Varma VR, Pettigrew C, Albert MS. African Americans and clinical research: evidence concerning barriers and facilitators to participation and recruitment recommendations. *Gerontologist*. 2017;57(2):348-358. <https://doi.org/10.1093/geront/gnv118> PMID:26553736
  17. Hennink MM, Kaiser BN, Marconi VC. Code saturation versus meaning saturation: how many interviews are enough? *Qual Health Res*. 2017;27(4):591-608. <https://doi.org/10.1177/1049732316665344> PMID:27670770
  18. Forman J, Damschroder J. Qualitative content analysis. In: Jacoby L, Siminoff L, eds. *Empirical Methods for Bioethics: A Primer*. Amsterdam: Jai Press Elsevier; 2008:39-62.
  19. Nápoles AM, Chadiha LA; Resource Centers for Minority Aging Research. Advancing the science of recruitment and retention of ethnically diverse populations. *Gerontologist*. 2011;51(suppl 1):S142-S146. <https://doi.org/10.1093/geront/gnr019> PMID:21565815
  20. Airhihenbuwa CO, Ford CL. Editorial: Critical race theory - we are all others. *Ethn Dis*. 2018;28(suppl 1):219-222. <https://doi.org/10.18865/ed.28.S1.219> PMID:30116089
  21. Royal C, Baffoe-Bonnie A, Kittles R, et al. Recruitment experience in the first phase of the African American Hereditary Prostate Cancer (AAHPC) study. *Ann Epidemiol*. 2000;10(8)(suppl):S68-S77. [https://doi.org/10.1016/S1047-2797\(00\)00194-0](https://doi.org/10.1016/S1047-2797(00)00194-0) PMID:11189095
  22. Dunn J. The concept of 'trust' in the politics of John Locke. In: Rorty R, Schneewind JB, Skinner Q, eds. *Philosophy in History*. Cambridge: Cambridge University Press; 1984. <https://doi.org/10.1017/CBO9780511625534.015>
  23. Dilworth-Anderson P, Cohen MD. Beyond diversity to inclusion: recruitment and retention of diverse groups in Alzheimer research. *Alzheimer Dis Assoc Disord*. 2010;24(suppl):S14-S18. <https://doi.org/10.1097/WAD.0b013e3181f12755> PMID:22720319
  24. Salimi Y, Shahandeh K, Malekafzali H, et al. Is Community-based participatory research (CBPR) useful? a systematic review on papers in a decade. *Int J Prev Med*. 2012;3(6):386-393. PMID:22783464
  25. De las Nueces D, Hacker K, DiGirolamo A, Hicks LS. A systematic review of community-based participatory research to enhance clinical trials in racial and ethnic minority groups. *Health Serv Res*. 2012;47(3 Pt 2):1363-1386. <https://doi.org/10.1111/j.1475-6773.2012.01386.x> PMID:22353031
  26. Barnes LL, Shah RC, Aggarwal NT, Bennett DA, Schneider JA. The Minority Aging Research Study: ongoing efforts to obtain brain donation in African Americans without dementia. *Curr Alzheimer Res*. 2012;9(6):734-745. <https://doi.org/10.2174/156720512801322627> PMID:22471868
  27. Hood S, Hall M, Dixon C, Jolly D, Linnan L. Organizational-level recruitment of barbershops as health promotion intervention study sites: addressing health disparities among Black men. *Health Promot Pract*. 2018;19(3):377-389. <https://doi.org/10.1177/1524839917696715> PMID:29161902
  28. Huffman LE, Wilson DK, Kitzman-Ulrich H, Lyerly JE, Gause HM, Resnicow K. Associations between culturally relevant recruitment strategies and participant interest, enrollment and generalizability in a weight-loss intervention for African American families. *Ethn Dis*. 2016;26(3):295-304. <https://doi.org/10.18865/ed.26.3.295> PMID:27440968
  29. Hart A Jr, Underwood SM, Smith WR, et al. Recruiting African-American barbershops for prostate cancer education. *J Natl Med Assoc*. 2008;100(9):1012-1020. [https://doi.org/10.1016/S0027-9684\(15\)31437-1](https://doi.org/10.1016/S0027-9684(15)31437-1) PMID:18807428
  30. Moreno-John G, Gachie A, Fleming CM, et al. Ethnic minority older adults participating in clinical research: developing trust. *J Aging Health*. 2004;16(5)(suppl):93S-123S. <https://doi.org/10.1177/0898264304268151> PMID:15448289
  31. Nápoles-Springer AM, Grumbach K, Alexander M, et al. Clinical research with older African Americans and Latinos - Perspectives from the community. *Res Aging*. 2000;22(6):668-691. <https://doi.org/10.1177/0164027500226004>
  32. Nápoles A, Cook E, Ginossar T, Knight KD, Ford ME. Applying a conceptual framework to maximize the participation of diverse populations in cancer clinical trials. *Adv Cancer Res*. 2017;133:77-94. <https://doi.org/10.1016/bs.acr.2016.08.004> PMID:28052822
  33. Ford JG, Howerton MW, Lai GY, et al. Barriers to recruiting underrepresented populations to cancer clinical trials: a systematic review. *Cancer*. 2008;112(2):228-242. <https://doi.org/10.1002/cncr.23157> PMID:18008363
  34. Moreno G, Mangione CM, Meza CE, et al. Perceptions from Latino and African American older adults about biological markers in research. *Ethn Dis*. 2015;25(3):355-362. <https://doi.org/10.18865/ed.25.3.355> PMID:26347148
  35. Zhou Y, Elashoff D, Kremen S, Teng E, Karlawish J, Grill JD. African Americans are less likely to enroll in preclinical Alzheimer's disease clinical trials. *Alzheimers Dement (N Y)*. 2016;3(1):57-64. <https://doi.org/10.1016/j.trci.2016.09.004> PMID:29067319
  36. Ballard EL, Gwyther LP, Edmonds HL. Challenges and opportunities: recruitment and retention of African Americans for Alzheimer disease research: lessons learned. *Alzheimer Dis Assoc Disord*. 2010;24(suppl):S19-S23. <https://doi.org/10.1097/WAD.0b013e3181f12432> PMID:20711060
  37. Lambe S, Cantwell N, Islam F, Horvath K, Jefferson AL. Perceptions, knowledge, incentives, and barriers of brain donation among African American elders enrolled in an Alzheimer's research program. *Gerontologist*. 2011;51(1):28-38. <https://doi.org/10.1093/geront/gnq063> PMID:20679141
  38. Epps F, Skemp L, Specht J. Using culturally informed strategies to enhance recruitment of African Americans in dementia research: a nurse researcher's experience. *J Res Pract*. 2015;11(1):1-17.
  39. Corbie-Smith G, Thomas SB, Williams MV, Moody-Ayers S. Attitudes and beliefs of African Americans toward participation in medical research. *J Gen Intern Med*. 1999;14(9):537-546. <https://doi.org/10.1046/j.1525-1497.1999.07048.x> PMID:10491242
  40. Williams MM, Scharff DP, Mathews KJ, et al. Barriers and facilitators of African American participation in Alzheimer disease biomarker research. *Alzheimer Dis Assoc Disord*. 2010;24(suppl):S24-S29. <https://doi.org/10.1097/WAD.0b013e3181f14a14> PMID:20711059
  41. Dilworth-Anderson P, Thaker S, Burke JM. Recruitment strategies for studying dementia in later life among diverse cultural groups. *Alzheimer Dis Assoc Disord*. 2005;19(4):256-260. <https://doi.org/10.1097/01.wad.0000190803.11340.66> PMID:16327355
  42. Earl CE, Penney PJ. The significance of trust in the research consent process with African Americans. *West J Nurs Res*. 2001;23(7):753-762. <https://doi.org/10.1177/01939450122045528> PMID:11675799
  43. Cameron JJ, Chu LM, Matte A, et al. RECOVER Program Investigators (Phase 1: towards RECOVER); Canadian Critical Care Trials Group. One-year outcomes

- in caregivers of critically ill patients. *N Engl J Med.* 2016;374(19):1831-1841. <https://doi.org/10.1056/NEJMoa1511160> PMID:27168433
44. Elo S, Kyngäs H. The qualitative content analysis process. *J Adv Nurs.* 2008;62(1):107-115. <https://doi.org/10.1111/j.1365-2648.2007.04569.x> PMID:18352969
  45. Crookall R, Fowler G, Wood C, Slade P. A systematic mixed studies review of women's experiences of perineal trauma sustained during childbirth. *J Adv Nurs.* 2018;74(9):2038-2052. <https://doi.org/10.1111/jan.13724> PMID:29791012
  46. Francis DO, Sherman AE, Hovis KL, et al. Life experience of patients with unilateral vocal fold paralysis. *JAMA Otolaryngol Head Neck Surg.* 2018;144(5):433-439. <https://doi.org/10.1001/jamaoto.2018.0067> PMID:29621392
  47. Petricca K, Bekele A, Berta W, Gibson J, Pain C. Advancing methods for health priority setting practice through the contribution of systems theory: lessons from a case study in Ethiopia. *Soc Sci Med.* 2018;198:165-174. <https://doi.org/10.1016/j.socscimed.2017.12.009> PMID:29367105
  48. Corbin J, Strauss A. *Basics of Qualitative Research.* Thousand Oaks, CA: Sage; 2008.
  49. Strauss A. *Qualitative Analysis for Social Scientists.* Cambridge, UK: Cambridge University Press; 1987. <https://doi.org/10.1017/CBO9780511557842>
  50. Huberman A, Miles M. Data management and analysis methods. In: Densin N, Lincoln Y, eds. *Handbook of Qualitative Research.* Thousand Oaks, CA: Sage Publishers; 1994.
  51. Portacolone E, Perissinotto C, Yeh JC, Greysen SR. "I feel trapped": The tension between personal and structural factors of social isolation and the desire for social integration among older residents of a high-crime neighborhood. *Gerontologist.* 2018;58(1):79-88. <https://doi.org/10.1093/geront/gnw268> PMID:28329804
  52. Kuzel A, Like R, eds. *Standard of Trustworthiness for Qualitative Studies in Primary Care.* Thousand Oaks, CA: Sage Publications; 1992.
  53. Farmer T, Robinson K, Elliott SJ, Eyles J. Developing and implementing a triangulation protocol for qualitative health research. *Qual Health Res.* 2006;16(3):377-394. <https://doi.org/10.1177/1049732305285708> PMID:16449687
  54. Miles M, Huberman A. *Qualitative Data Analysis: A Sourcebook of New Methods.* Beverly Hills, CA: Sage Publishers; 1984.
  55. Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *Int J Qual Health Care.* 2007;19(6):349-357. <https://doi.org/10.1093/intqhc/mzm042> PMID:17872937
  56. Lu D, Palmer JR, Rosenberg L, et al. Perceived racism in relation to telomere length among African American women in the Black Women's Health Study. *Ann Epidemiol.* 2019;36:33-39. <https://doi.org/10.1016/j.annepidem.2019.06.003> PMID:31387775
  57. Cozier YC, Coogan PF, Govender P, Beriman JS, Palmer JR, Rosenberg L. Obesity and weight gain in relation to incidence of sarcoidosis in US black women: data from the Black Women's Health Study. *Chest.* 2015;147(4):1086-1093. <https://doi.org/10.1378/chest.14-1099> PMID:25411869
  58. Hill CV. At the intersection of rigor and equity: health disparities research related to aging. *Gerontol Geriatr Med.* 2019. <https://doi.org/10.1177/2333721419857858> PMID:31321254
  59. Shavers-Hornaday VL, Lynch CF, Burmeister LF, Torner JC. Why are African Americans under-represented in medical research studies? Impediments to participation. *Ethn Health.* 1997;2(1-2):31-45. <https://doi.org/10.1080/13557858.1997.9961813> PMID:9395587
  60. Jamison AM, Quinn SC, Freimuth VS. "You don't trust a government vaccine": narratives of institutional trust and influenza vaccination among African American and white adults. *Soc Sci Med.* 2019;221:87-94. <https://doi.org/10.1016/j.socscimed.2018.12.020> PMID:30576982
  61. Harris LM, Chin NP, Fiscella K, Humiston S. Barrier to pneumococcal and influenza vaccinations in Black elderly communities: mistrust. *J Natl Med Assoc.* 2006;98(10):1678-1684. PMID:17052061
  62. Quinn S, Jamison A, Musa D, Hilyard K, Freimuth V. Exploring the continuum of vaccine hesitancy between African American and White adults: results of a qualitative study. *PLoS Curr.* 2016;8:8. <https://doi.org/10.1371/currents.outbreaks.3e4a5ea39d8620494e2a2c874a3c4201> PMID:28239512
  63. Jacobs EA, Rolle I, Ferrans CE, Whitaker EE, Warnecke RB. Understanding African Americans' views of the trustworthiness of physicians. *J Gen Intern Med.* 2006;21(6):642-647. <https://doi.org/10.1111/j.1525-1497.2006.00485.x> PMID:16808750
  64. Scharff DP, Mathews KJ, Jackson P, Hoffsuemmer J, Martin E, Edwards D. More than Tuskegee: understanding mistrust about research participation. *J Health Care Poor Underserved.* 2010;21(3):879-897. <https://doi.org/10.1353/hpu.0.0323> PMID:20693733
  65. Murray TM. Trust in African Americans' healthcare experiences. *Nurs Forum.* 2015;50(4):285-292. <https://doi.org/10.1111/nuf.12120> PMID:25612227
  66. Brave Heart MY. The historical trauma response among natives and its relationship with substance abuse: a Lakota illustration. *J Psychoactive Drugs.* 2003;35(1):7-13. <https://doi.org/10.1080/02791072.2003.10399988> PMID:12733753
  67. Gilson L. Trust and the development of health care as a social institution. *Soc Sci Med.* 2003;56(7):1453-1468. [https://doi.org/10.1016/S0277-9536\(02\)00142-9](https://doi.org/10.1016/S0277-9536(02)00142-9) PMID:12614697
  68. Giddens A. *The Consequences of Modernity.* Cambridge, UK: Cambridge University Press; 1990.
  69. Lang R, Kelkar VA, Byrd JR, Edwards CL, Pericak-Vance M, Byrd GS. African American participation in health-related research studies: indicators for effective recruitment. *J Public Health Manag Pract.* 2013;19(2):110-118. <https://doi.org/10.1097/PHH.0b013e31825717ef> PMID:23358288
  70. Shavers VL, Lynch CF, Burmeister LF. Racial differences in factors that influence the willingness to participate in medical research studies. *Ann Epidemiol.* 2002;12(4):248-256. [https://doi.org/10.1016/S1047-2797\(01\)00265-4](https://doi.org/10.1016/S1047-2797(01)00265-4) PMID:11988413
  71. Byrd GS, Edwards CL, Kelkar VA, et al. Recruiting intergenerational African American males for biomedical research Studies: a major research challenge. *J Natl Med Assoc.* 2011;103(6):480-487. [https://doi.org/10.1016/S0027-9684\(15\)30361-8](https://doi.org/10.1016/S0027-9684(15)30361-8) PMID:21830630
  72. Saha S, Jacobs EA, Moore RD, Beach MC. Trust in physicians and racial disparities in HIV care. *AIDS Patient Care STDS.* 2010;24(7):415-420. <https://doi.org/10.1089/apc.2009.0288> PMID:20578909
  73. Russell E, Robinson DH, Thompson NJ, Perryman JP, Arriola KR. Distrust in the healthcare system and organ donation intentions among African Americans. *J Community Health.* 2012;37(1):40-47. <https://doi.org/10.1007/s10900-011-9413-3> PMID:21626439
  74. McDonald EL, Powell CL, Perryman JP, Thompson NJ, Arriola KR. Understanding the relationship between trust in health care and attitudes toward living donor transplant among African Americans with end-stage renal disease. *Clin Transplant.* 2013;27(4):619-626. <https://doi.org/10.1111/ctr.12176> PMID:23786436
  75. Izquierdo A, Ong M, Jones F, Jones L, Ganz D, Rubenstein L. Engaging African American veterans with health care access challenges in a community partnered care coordination initiative: a qualitative needs assessment. *Ethn Dis.* 2018;28(suppl 2):475-484. <https://doi.org/10.18865/ed.28.S2.475> PMID:30202201
  76. Kelley AS, McGarry K, Gorges R, Skinner JS. The burden of health care costs for patients with dementia in the last 5 years of life. *Ann Intern Med.* 2015;163(10):729-736. <https://doi.org/10.7326/M15-0381> PMID:26502320
  77. Kuehn BM. Race may influence transplant decision making in heart failure: studies also detail disparities in hypertension diagnosis, statin prescribing. *Circulation.* 2020;141(8):694-

695. <https://doi.org/10.1161/CIRCULATIONAHA.120.045853> PMID:32091930
78. Otado J, Kwagyan J, Edwards D, Ukaegbu A, Rockcliffe F, Osafo N. Culturally competent strategies for recruitment and retention of African American populations into clinical trials. *Clin Transl Sci.* 2015;8(5):460-466. <https://doi.org/10.1111/cts.12285> PMID:25974328
79. Hood KB, Hart A Jr, Belgrave FZ, Tademey RH, Jones RA. The role of trust in health decision making among African American men recruited from urban barbershops. *J Natl Med Assoc.* 2012;104(7-8):351-359. [https://doi.org/10.1016/S0027-9684\(15\)30176-0](https://doi.org/10.1016/S0027-9684(15)30176-0) PMID:23092050
80. Horn IB, Mitchell SJ, Wang J, Joseph JG, Wisow LS. African-American parents' trust in their child's primary care provider. *Acad Pediatr.* 2012;12(5):399-404. <https://doi.org/10.1016/j.acap.2012.06.003> PMID:22858071
81. Valantine HA, Collins FS. National Institutes of Health addresses the science of diversity. *Proc Natl Acad Sci USA.* 2015;112(40):12240-12242. <https://doi.org/10.1073/pnas.1515612112> PMID:26392553
82. Carnethon MR, Kershaw KN, Kandula NR. Disparities research, disparities researchers, and health equity. *JAMA.* 2020;323(3):211-212. PMID:31841578
83. Tiernan C, Lysack C, Neufeld S, Lichtenberg PA. Community engagement: an essential component of well-being in older African-American adults. *Int J Aging Hum Dev.* 2013;77(3):233-257. <https://doi.org/10.2190/AG.77.3.d> PMID:24340874
84. Goddard J, Coombes M, Kempton L, Valance P. Universities as anchor institutions in cities in a turbulent funding environment: vulnerable institutions and vulnerable places in England. *Camb J Regions Econ Soc.* 2014;7(2):307-325. <https://doi.org/10.1093/cjres/rsu004>
85. Koh HK, Bantham A, Geller AC, et al. Anchor institutions: best practices to address social needs and social determinants of health. *Am J Public Health.* 2020;110(3):309-316. <https://doi.org/10.2105/AJPH.2019.305472> PMID:31944837
86. Pinderhughes R, Bui A, Alexander B, King B, Emily M, O'nda T. *Advancing Health Equity in San Francisco: An Assessment of UCSF's Anchor Institution Capacity and Recommendation for Strategic Direction.* San Francisco, CA: University of California San Francisco. The San Francisco Foundation; 2019.