


Exploring the Reasons Urban and Rural-Dwelling Older Adults Participate in Memory Research

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Amanda Hunsaker, MPH¹, C. Elizabeth Sarles, MPH², Daniel Rosen, PhD, MSW¹, Jennifer H. Lingler, PhD, RN, FNP³, Marla Bonacile Johnson, EdD⁴, Lisa Morrow, PhD⁵, and Judith Saxton, PhD⁶

Abstract

This study examines how underrepresented older urban and rural-dwelling individuals conceptualize participation in cognitive impairment studies. Nine focus groups were held with urban and rural-dwelling older adults who had participated in a community-based memory screening study. Expected and experienced benefits of research participation were motivators for study participation in all focus groups. Results indicate that participation in memory research was believed to lead to an understanding of memory function. Focus group participants expressed an active interest in research on dementia, and viewed research participation as a way to address memory concerns and provide a benefit to society.

Keywords

underrepresented older adults, research participation, dementia, mild cognitive impairment, focus groups

Introduction

Historically in the United States, cognitive impairment study samples have been comprised of suburban-dwelling, educated white individuals, with significant underrepresentation of individuals from urban and rural-dwelling communities.¹ Urban communities in particular may have a significantly greater diversity in ethnic and racial composition that is often lacking in studies of dementia and mild cognitive impairment (MCI). In response to funding guidelines provided by the National Institute on Aging, federally-funded Alzheimer Disease Centers (ADCs) across the United States are exploring and incorporating methods aimed at increasing research participation from underrepresented groups. Guidelines for ADCs strongly encourage applicants to incorporate programming that addresses “the needs of, and research on, ethnically and racially diverse people as well as underserved populations,” such as individuals living in rural areas.²

Reasons underlying the exclusion of underrepresented individuals have been widely studied³ and further research has focused on exploring recruitment and retention protocols that enhance participation from urban and rural communities.^{4,5} Issues with underrepresentation of racial and geographic populations have arisen specifically within dementia and MCI research,⁶ where misinformation and stigma regarding dementia compound the complexity of involving underrepresented groups in memory-related studies.^{7,8}

There are a number of reasons why it is critical to include individuals with varying racial and ethnic backgrounds, as well

as individuals from varying geographic regions of the country. Individuals in rural communities may differ in educational level from those residing in urban areas.⁹ In memory screening protocols, ceiling and floor effects may appear within populations of different levels of education and cultural backgrounds.¹⁰ Establishing normative data for specific populations is crucial prior to applying any test as a community-wide screening tool.¹⁰

In order to increase urban and rural-dwelling individuals' involvement in memory research, it is paramount to understand the reasons older urban or rural-dwelling individuals might participate in a research study, including what benefits and drawbacks individuals believe are associated with memory research participation. As the field of cognitive research moves more toward studies of individuals who are experiencing the

¹ School of Social Work, University of Pittsburgh, Pittsburgh, PA

² Alzheimer Disease Research Center, Department of Neurology, University of Pittsburgh School of Medicine, Pittsburgh, PA

³ Department of Health and Community Systems, University of Pittsburgh School of Nursing, Pittsburgh, PA

⁴ Bonacile Enterprises, Pittsburgh, PA

⁵ Department of Psychiatry, University of Pittsburgh School of Medicine, Pittsburgh, PA

⁶ Department of Neurology, University of Pittsburgh School of Medicine, Pittsburgh, PA

Corresponding Author:

Amanda Hunsaker, 2117 Cathedral of Learning, Pittsburgh, PA, 15260, USA
Email: aeh30@pitt.edu

very earliest indications of cognitive problems, recruitment becomes particularly difficult, especially within certain communities where there may be tendencies to normalize cognitive decline or a general reluctance to participate in research studies.

Nine focus groups were held with older urban and rural-dwelling individuals (both whites and African Americans) who had participated in a community-based memory screening study. The purpose of this study is to explore the reasons that older, community-dwelling individuals, who are typically underrepresented in research, participate in studies and how research participants viewed their research experience.

Methods

Participants

Participants were a purposive sample of older adults who had participated in a community-based memory screening study, the Memory and Aging in Urban and Rural Communities (MAURC) Study. The primary aim of the MAURC study was to evaluate the use of a memory screening tool in 2 underserved populations, primarily African American older adults living in urban areas and rural-dwelling older adults.

In order to participate in the MAURC study, individuals had to be community-dwelling, age 65 years or older, an English speaker, have >6 years of education, adequate vision and hearing to complete neuropsychological testing, and a reliable proxy who could provide information about the participant's overall functioning. Participants were asked to complete a computerized memory screening tool annually for up to 3 years, in addition to 2 standardized neurocognitive tests. Memory screening was completed in home and community settings and participants received up to US\$45 for participating. Results of testing were not shared with participants as the primary aim was to determine the effectiveness of the computerized assessment.

A second aim of the MAURC study was to determine the agreement between the community diagnosis of cognitive impairment, provided via the computerized memory screening, and a comprehensive assessment provided by the University of Pittsburgh Alzheimer Disease Research Center (ADRC). The day-long ADRC evaluation included a neurological and psychiatric evaluation, brain imaging, a comprehensive neuropsychological assessment, and a psychosocial evaluation.¹¹

A total of 657 older adults participated in the MAURC study, exceeding planned recruitment targets, and 70 MAURC participants completed the ADRC assessment. Due to the study's success in meeting its recruitment goals, a series of focus groups were held to explore why individuals were interested in participating in the MAURC study and the ADRC.

Design

Nine focus groups were conducted that were homogenous in composition (ie, all rural-dwelling or all urban-dwelling) and included 3 focus groups with rural-dwelling and 6 with urban-dwelling participants. At the beginning of each group,

a moderator reviewed a verbal consent form, including the focus group procedures. Participants were asked if they had any questions or concerns about the focus group procedures, and whether they consented to participating.

Focus groups were audiorecorded and notes were recorded by a note taker. Groups ranged in size from 3 to 10 participants. In order to have sufficient participant representation overall and to make groups convenient for participants, the investigators decided to hold focus groups even when participation was low. The institutional review board of the University of Pittsburgh approved all procedures.

Measures

Each focus group was conducted using an interview guide developed through collaboration with researchers of diverse backgrounds (nursing, neuropsychology, education, social work, and public health). Community members, including research staff for the rural arm of the parent study and members of the ADRC Community Advisory Council, a group formed to advise on ADRC outreach to African Americans, also provided feedback during the development of the focus group interview guide. The guide was comprised of 5 question areas: (a) "What words come to mind when you hear the word research?" (b) "What did you think about the MAURC study before you participated?" (c) "Was it what you expected? How was it or how wasn't it?" and (d) "How did your own experiences and the experiences of your peers change/or not change your thinking about research?" The final question explored participants' views on their involvement in the ADRC or their level of interest in participating in the ADRC if they had not been recruited to the memory assessment program. Demographic data were abstracted from MAURC study records.

Data Analysis

Focus group audiorecordings were transcribed verbatim and compiled with nonverbal statements (eg, head nodding, eye contact) captured by each note-taker. The goals of analysis were to characterize the reasons people participated in the memory studies and their perceptions of the experience. It is important to note that deriving differences between the rural and urban focus groups was not a primary goal of data analysis. With an eye toward the stated goals, and through listening to the audiorecordings and multiple readings of transcripts by various team members, preliminary codes were assigned to the text and discussed among 3 of the authors (AEH, DR, CES). The process of content analysis was then employed and codes were assigned to sections of the text.¹² Codes were developed from wording that appeared within the transcripts and were further described as needed to distinguish between codes. For example, some participants discussed how their research participation could benefit their own family members, while others talked of research participation benefiting future generations more globally. Additionally, participants described benefits that were expected from study participation versus

Table 1. Sample Demographics

| Characteristics | Urban-Dwelling (N = 32) | Rural-Dwelling (N = 23) | Total (N = 55) |
|---------------------------------|-------------------------|-------------------------|----------------|
| Female | 26 (81.2%) | 16 (69.6%) | 42 (76.4%) |
| Race | | | |
| African American | 32 (100%) | 4 (17.4%) | 36 (65.5%) |
| White | 0 (0%) | 19 (82.6%) | 19 (34.5%) |
| Mean age, range | 74.06 (66-90) | 76.30 (66-87) | 75.00 (66-90) |
| Education | | | |
| Less than HS | 2 (6.2%) | 1 (4.3%) | 3 (5.5%) |
| HS/GED | 12 (37.5%) | 15 (65.2%) | 27 (49.1%) |
| Certificate/associate's degree | 10 (31.2%) | 1 (4.3%) | 11 (20.0%) |
| Bachelor's degree | 2 (6.2%) | 3 (13.0%) | 5 (9.1%) |
| Graduate/Postgraduate | 6 (18.7%) | 3 (13.0%) | 9 (16.3%) |
| ADRC participation ^a | 14 (43.8%) | 9 (39.1%) | 23 (41.8%) |

Abbreviations: ADRC, Alzheimer Disease Research Center; HS, high school; GED, General Equivalency Diploma.

^a Seven urban-dwelling focus group participants were participants of the ADRC prior to joining the Memory and Aging in Urban and Rural Communities (MAURC) study. One rural-dwelling participant participated in the ADRC as a study partner, providing information regarding another participant's memory status during the ADRC memory assessment. All are counted as ADRC participants.

benefits that were actually experienced as an outcome of their study involvement. Multiple codes were assigned to sections of the text as appropriate. For example, some participants spoke of their experiences caring for a loved one with memory problems leading them to research participation, in the hopes of helping others. Each transcript was read and coded by the first author and sections of the transcripts were also coded by a coinvestigator (CES). Memos were additionally created by the first author, then shared and discussed with 3 co-investigators (CES, DR, JHL). As patterns emerged from the codings, related codes were grouped into overarching categories that became conceptualized as primary themes. Through an inductive method of coding, where prior themes had not been determined before the transcripts were analyzed, the benefits of research study participation emerged as the overarching theme of the focus groups. Analysis continued in this iterative fashion until theoretical saturation was reached.¹³ Finally, a feedback session was held with the ADRC Community Advisory Council, in which the preliminary results of the focus groups were presented in order to validate our interpretation of the findings.

Results

A total of 55 participants attended focus group sessions, including 23 participants from rural areas and 33 participants from urban areas. Table 1 characterizes the sample by focus group location (urban versus rural). All urban-dwelling participants were African American while African Americans comprised 17% of rural-dwelling participants. In accordance with our purposive sampling method, in every focus group, at least 1 participant had agreed to participate in the ADRC memory assessment.

The expected and experienced benefits related to research participation were a primary focus of discussion in every group, and were conceived as both antecedent experiences leading to research participation and expected benefits derived

from research participation. Benefits impacting the study participant were discussed in all groups, while those impacting family members were discussed in 5 groups and those impacting society were discussed in 7 groups.

Benefiting the Participant

Those benefits perceived to be gained by the participant from research involvement centered around 4 main expectations of, or outcomes associated with, research participation: (1) understanding memory changes with aging; (2) accessing health services; (3) financially benefiting, and (4) promoting research awareness. Overall discussion of benefits focused more on experienced than expected benefits.

Understanding memory changes with aging. Participation in memory research was considered by many focus group participants as a means to gain an understanding of how their memory was functioning. It should be noted that for MAURC study participants, this understanding of memory function was in absence of any feedback from the study team regarding their memory status. Discussions of this finding with the MAURC investigators revealed that participant misconceptions related to MAURC study participation had indeed been noted throughout recruitment and testing, with efforts made to explain that results of testing would not be provided. In 2 focus groups, participants discussed the notion that study participation provided a mental challenge. Stated a rural-dwelling participant (group 9), "But we needed it. You get to a certain age, we're not out with the public, we're not working or anything. So we need to get our brains working. We need something to keep us you know our brains."

Others discussed how study participation brought them a sense of relief, based on their perception of having performed well in the MAURC study. In 1 urban focus group (group 2), 2 participants both voiced relief that they were "not the only

one” experiencing memory changes, and those memory changes were deemed a normal part of aging. Another rural-dwelling participant (group 7) felt relief at doing well on testing, when he knew that his father experienced cognitive problems at his age and perceived cognitive decline as inevitable due to family history. Another participant felt a sense of confidence in recognizing memory changes as a result of normal aging. This participant (urban, group 5) explained:

... it helps give you confidence too to know where you are. Because your mind will be telling you all kind of things and then when you go through the study you realize that a lot of things that you're going through, they're just normal stages of aging.

While confidence and relief were gained by some focus group members as they gauged their performance on memory testing, others discussed gaining a heightened awareness of their mental abilities from study participation. This awareness took the form of being able to identify the areas they felt they had shortcomings in, or whether they were experiencing a progressive, overall change in their memory performance, with progression generally considered as a decline in performance.

Heightened attentiveness to memory changes included an awareness of change in recall and concentration abilities. These memory changes noted by participants during testing were also linked to day-to-day activities, such as remembering an acquaintance's name, balancing the checkbook, or driving. For example, 1 participant (rural, group 7) described having an increased awareness of concentration level when driving: "... it made me more aware that when I'm driving that I don't notice the things on the sides of the road, that I just go always in a hurry ... and I'm not aware of what's happening on the signs on the road, you know?" This comment was made in relation to a driving simulation that is included in the computerized memory screening tool.

By gaining an understanding of weaknesses in memory performance through research participation, 2 focus group participants spoke about the methods they have employed to improve their performance in daily activities. As 1 participant (rural, group 8) shared, "Now when I'm traveling in a strange place, I look and see what's on that corner when you make your turn. That way when I go there the next time I know where to go" Another individual (urban, group 3), who is also a participant in the ADRC, shared their self-initiated changes made in activities based on self-impressions of performance on memory testing, as well as the feedback received from the ADRC. Self-impressions included noticing changes in "instant recall," leading the participant to ask for assistance from family members in managing finances. This participant discussed balancing the desire to maintain independence, while recognizing and responding to limitations: "My reason [for research participation] is I want to live alone and I want to continue to live alone ... so I want to do everything I can to help myself and you know keep going."

Providing health services. While much of the dialogue focused on the benefits of understanding memory performance, others discussed the experienced benefit of having ongoing health care screening and services available through research participation. Two participants spoke about how health conditions, such as vitamin deficiency and stroke, were identified through memory assessments at the ADRC. Overall, participants expressed how participating in health studies helped manage as well as detect health problems. In 3 focus groups, participants discussed their participation in other research studies leading to treatment and management of health issues. One rural-dwelling participant (group 6) stated: "If they never had research I would have never found out that I had cancer." For this participant, a direct relationship was made between research participation and discovering a serious health condition.

Providing financial benefits. Receiving compensation for participating in a research study was noted by 3 urban focus groups, yet it was not discussed in any of the rural focus groups. As 1 urban-dwelling participant (group 2) related to the group when asked what sparked interest in participating in the MAURC study: "The money ... That first. And the second time, to be truthful the third time."

Participants in urban focus groups also felt that financial compensation would be a motivator for others to participate in research studies. Compensation through transportation to and from the study site was also viewed favorably. In fact, for rural participants, transportation was a primary concern for participation in the ADRC. In these groups, the participants who completed an ADRC assessment discussed how they would not have done so if transportation was not provided. Each rural-dwelling group went on to spontaneously brainstorm ways to provide transportation for continued ADRC participation. Within urban groups, transportation was discussed as a benefit but was not considered a deciding factor.

Promoting research awareness. In 6 focus groups, discussion centered on what it meant to participate in research. One rural-dwelling group member felt that it was especially important for women of her generation to participate in research studies, as she believed there was a lessened likelihood that they would have been exposed to research earlier in life. One participant shared how research participation had changed her views on research. "And one thing it did help 'cause I was like a skeptical about research and it helped change my view ... by actually being a participant" (urban, group 5).

Benefiting the Participant's Family

In 2 focus groups, discussion touched on the importance of family involvement in research studies and the benefit that may be derived by family members of research participants. Overall, participants highlighted the expected benefits of research participation for family members, rather than experienced benefits. One participant described how family involvement in research can provide family members with an enhanced

understanding of the disease process of dementia and contextualize the memory changes that family members are noting. This participant went on to say that involvement in research can also combat family denial of memory changes: “I think the studies are good to help family members ‘cause a lot of denial comes from family who don’t – who wonder why their loved one is acting like that, ‘What’s she doing that for?’ you know because they don’t understand . . .” (urban, group 1). An urban-dwelling ADRC participant (group 3) encouraged family members to learn more about the participant’s research experiences in light of receiving a diagnosis of MCI or dementia. This participant went on to say that family members’ increased awareness could aid in the process of coming to terms with the participant’s need for increased assistance, and help to anticipate future areas in which the participant might need support.

While potentially assisting in the present-day issues families face when a loved one experiences memory impairment, research participation was also expected to benefit families in the long term, through a better understanding of family health history. Participants felt that the hereditary nature of AD meant that it was critical for later generations to know whether their family member had been diagnosed with memory impairment. To illustrate this concept 1 participant stated, “So I know something already and I pass that down to my children so they can pass it down . . .” (urban, group 6). Others felt that their research participation was potentially leading to treatments that could benefit future generations.

Benefiting Society

Seven focus groups discussed the societal benefits of research, mentioning both expected and experienced benefits of research participation. One participant (urban, group 5) spoke of ongoing participation in the ADRC: “But at first I was getting tired of doing it but I said, ‘No, I’m gonna keep on because this is helping me as well as helping somebody else.’” In several cases, societal and personal benefits were considered to be congruent.

Helping future generations. In 4 groups, the notion of helping future generations, more generally than their own family members, was discussed as a strong motivator for participation in memory research. One urban-dwelling participant (group 4) shared a view that research participation is critical for enhancing the lives of future generations: “And I hope through our study, what we’re taking, what we’re going through, there’s some benefit for those who will follow us.”

Benefiting research progress. Discussion of benefiting research progress centered on finding a cure for AD and improving dementia treatment, and was explored in 5 focus groups. Several participants also discussed the importance of investigating new medications and viewed this as a positive output from research participation. One participant (rural, group 9) described how she initially decided to participate in the MAURC study: “I

thought it would be good because I think Alzheimer’s is such a terrible disease and if we could help to find a cure or better treatment or some way to stop it, I think it’s really worthwhile and we should do all we could.”

Antecedents of Dementia and MCI Research Participation

In 8 focus groups, life experiences leading to research participation were discussed, often in relation to the benefits expected from study participation. These experiences included having first-hand knowledge of AD or dementia (ie, having a family history of AD, caring for someone with AD, or knowing someone with AD), experiencing memory changes (ie, losing something or forgetting the reason for entering a room), and having previously participated in a research study.

Participants noted that individuals with a family history of memory impairment would particularly benefit from research participation. Other participants talked about having family members or friends with AD, and how this experience had led them to research participation with the hope of a societal benefit to future generations. A rural-dwelling participant (group 9) stated, “And like I was gonna say, . . . if you’ve lived with somebody that’s had it and you know what you’re going through it . . . I kind of think I wanna try and help the future if I can.” Participants also spoke of their experiences of caring for someone with dementia, and their grief as the person declined. They felt study participation gave them a way “to do something about it” (rural, group 7) or to contribute to the progress of research.

Many focus group participants described experiences of losing an important item or forgetting an appointment, triggering involvement in the memory screening study. An urban-dwelling participant (group 5) stated,

I joined the study because I was concerned . . . and I got to thinking, “Well I shouldn’t be forgetting things. There’s something I’m supposed to do but I can’t remember what it is.” . . . So . . . I said, “I’m doing that study just in case.”

Finally, discussion of previous participation in research occurred in several focus groups. While participants did not relate their recent participation in the MAURC study as guided by participating in past studies, past experiences of research participation do imply a trust of research studies and the research community. In each case, participants described a benefit gained from their previous research participation, and benefits were believed to impact both the participant and society.

Discussion

The purpose of this study was to explore the reasons individuals from underrepresented communities—urban-dwelling and rural-dwelling older adults—may participate in MCI and dementia research. Experienced and expected benefits fell into the categories of participant benefit, family benefit, and

societal benefit. The most commonly discussed benefit was the expected and experienced outcome of gaining an understanding of memory status, followed by enhanced research awareness. Participants additionally described altruistic motives for research participation, including the expected benefits of helping future generations or benefiting research progress. Finally, participants believed that benefits existed for family members, by providing an understanding of the disease process of dementia or increased awareness of family health history.

Previous studies have explored the benefits that may potentially lead individuals to participate in research with varying results regarding the importance of participant and societal benefits.¹⁴⁻¹⁷ While studies are in general agreement regarding the types of benefits that are perceived to be gained or that motivate individuals to participate in research, findings differ regarding the relative importance of certain perceived benefits over others. Some researchers have cited altruism as a primary motivator for study participation,¹⁴ while other studies have reported that personal benefits to the participant, such as improvement in or identification of a health condition, were considered equally important to altruistic reasons.^{17,18} Cohen-Mansfield¹⁹ has suggested that individuals with dementia may be especially inclined to participate in studies for altruistic reasons because they may feel limited in opportunities to engage in meaningful activities that may benefit others. A focus group study exploring caregivers' attitudes toward their family members' participation in AD research found motivating factors included the opportunity to help the care recipient access care and treatment, advancing research, and receiving emotional support from research staff.¹⁶ Further, lack of a perceived benefit to participants' family members created a barrier to research participation. A 2-stage retrospective study reported that motivators to research participation can fluctuate over the course of the study¹⁸ and a more recent survey of ADRC participants has documented that temporal changes in willingness to participate in AD research can occur.²⁰ Overall, perceived benefits related to research participation may be significant indicators of recruitment and retention study outcomes, but are likely to change over time.

It is interesting to note that none of the focus groups in the current study discussed the importance of underrepresented individuals being involved in research, although this aspect of the MAURC study was often introduced to potential participants during the recruitment phase. A recent focus group study exploring the barriers and facilitators of participation in Alzheimer disease biomarker research among African Americans found that relevance of the study to the individual and their communities, as well as altruism, were motivators for research participation.²¹ Of note, the relevance of the study to the African American community was also viewed as a primary motivator to participate. Other work has corroborated that study value to the African American community may impact willingness to participate among African Americans.¹⁵ Further exploration of how underrepresented individuals view the impact of research on their community group is certainly warranted.

Additionally, while several studies have examined the attitudes of African Americans and older adults regarding

research participation, few studies have explored the attitudes of rural elders regarding study involvement.²² A self-report survey study of rural caregivers and care recipients with AD found that individuals with AD were significantly more interested in participating in memory loss research studies than their caregiver counterparts.²² The views of rural elders regarding dementia and MCI study participation are critical to tease out, as this subgroup comprises one quarter of those aged 65 and over who are at great risk for developing Alzheimer's disease and other dementias.²³ Targeted recruitment strategies, including contact with community gatekeepers, with a sensitivity of community structure and community needs, are reported to be particularly effective in rural communities.⁴

The primary difference arising between rural and urban focus groups was that urban groups discussed the importance of financial compensation, while all rural groups discussed the importance of transportation for ADRC participation. One report on barriers to AD research participation among African Americans asserted that elders living on limited or fixed incomes may need financial motivators to participate in research.²⁴ Work has shown that while study payment will increase willingness to participate, it does not necessarily blind individuals to the risk of study participation.²⁵ A small exploratory study of unpaid participants' views regarding study compensation found that payment was deemed appropriate when it reimbursed costs to the participant, was used to enhance study recruitment, or to recognize the time investment by the participant.²⁶ Overall, payment of study participants should be approached in an ethical manner that both accounts for any costs to the participant and recognizes the participant's contribution to research advancement.

Rural-dwelling individuals perceived few barriers to the community-based partner study, which was conducted at senior centers and social-service organizations based in rural counties, yet provision of transportation to the ADRC was considered by participants to be a requirement for participation in the ADRC assessment. Most rural participants stated that they would not be able to participate in the ADRC if transportation was not provided, and, in several cases, individuals were not interested in ADRC participation solely because of the transportation burden. This finding points to the importance of weighing the burden of transportation on the study participant in which case additional compensation for the participant should be taken into consideration in study budgeting.

For rural-dwelling individuals hesitant to travel to urban centers, exploring technologies that allow remote participation in research should additionally be a focus of consideration. Using telemedicine technology for neurocognitive assessment has been shown to be a reliable and valid means of administration^{27,28} and to provide accurate diagnoses for patients newly diagnosed with dementia.²⁹ Overall, enhancing funding opportunities for memory disorders clinics to expand research involvement of rural-dwelling individuals, either through transportation budgeting or the further development and utilization of telemedicine technology, may address rural research involvement.

The expected benefits of research that may be perceived by the study participant can weigh heavily on the decision to participate in research. It is critical for the researcher to have an understanding of how study participants view the benefits of research, as they may very well differ from the standard components of the risk: benefit ratio that are described in the study consent form. Study staff should be prepared to address the reasons that one might participate in research in an ethical and culturally appropriate manner, as reasons may significantly range from altruistic motivations to personal benefit from health care services and financial compensation. Approaching patients and families as a group when appropriate may be beneficial, as well as keeping family members apprised of the participant's progress in the study.³⁰ As our focus group participants viewed a benefit to be gained from their study participation by family members, this seems especially critical.

Issues of therapeutic misconception within nontherapeutic research are also essential to address with potential study participants. In this study, many of the focus groups discussed a high level of expectation of gaining an understanding of their memory status, yet this was not the primary aim of the community-based memory screening study, since the screening tool was undergoing evaluation. Researchers need to be aware that participants may be overwhelmingly inclined to assume that there are direct benefits to research participation, when none may actually exist.

Some limitations in the current study should be noted. Since the focus groups corresponded with the conclusion of the MAURC study, MAURC study participants who had withdrawn or been lost to follow-up could not be contacted for focus group participation. The research team was therefore unable to entirely capture the experiences of individuals who had a negative response to their research participation. Additionally, those who agreed to focus group participation may have been more likely to hold a generally positive opinion of study participation.

In conclusion, we found that focus groups participants from underserved communities have an active interest in research on dementia and MCI, and view research participation as a means to address both memory concerns and provide a benefit to society. In light of recruitment mandates from the NIH, understanding how individuals from underrepresented communities perceive research participation is critical for developing and implementing effective recruitment protocols. Increasing awareness of research opportunities within these underrepresented communities, through partnerships with community-based organizations and the employment of outreach staff who have extensive knowledge of the target community, will be a gain for both the participant and the advancement of effective research on dementia assessment and treatment strategies in our increasingly diverse population.

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Declaration of Conflicting Interests

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