



11-20-2021

Overcoming the COVID-19 Pandemic for Dementia Research: Engaging Rural, Older, Racially and Ethnically Diverse Church Attendees in Remote Recruitment, Intervention and Assessment

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Wiese, Lisa Kirk; Williams, Ishan C.; Schoenberg, Nancy E.; Galvin, James E.; and Lingler, Jennifer, "Overcoming the COVID-19 Pandemic for Dementia Research: Engaging Rural, Older, Racially and Ethnically Diverse Church Attendees in Remote Recruitment, Intervention and Assessment" (2021). *Behavioral Science Faculty Publications*. 73.
https://uknowledge.uky.edu/behavsci_facpub/73

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Digital Object Identifier (DOI)

<https://doi.org/10.1177/23337214211058919>


Notes/Citation Information

Published in *Gerontology and Geriatric Medicine*, v. 7.

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Gerontology & Geriatric Medicine
Volume 7: 1–9
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sagepub.com/journals-permissions
DOI: 10.1177/23337214211058919
journals.sagepub.com/home/ggm


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Abstract

Background: Access to cognitive screening in rural underserved communities is limited and was further diminished during the COVID-19 pandemic. We examined whether a telephone-based cognitive screening intervention would be effective in increasing ADRD knowledge, detecting the need for further cognitive evaluation, and making and tracking the results of referrals.

Method: Using a dependent t-test design, older, largely African American and Afro-Caribbean participants completed a brief educational intervention, pre/post AD knowledge measure, and cognitive screening.

Results: Sixty of 85 eligible individuals consented. Seventy-percent of the sample self-reported as African American, Haitian Creole, or Hispanic, and 75% were female, with an average age of 70. AD knowledge pre-post scores improved significantly ($t(49) = -3.4, p < .001$). Of the 11 referred after positive cognitive screening, 72% completed follow-up with their provider. Five were newly diagnosed with dementia. Three reported no change in diagnosis or treatment. Ninety-percent consented to enrolling in a registry for future research.

Conclusion: Remote engagement is feasible for recruiting, educating, and conducting cognitive screening with rural older adults during a pandemic.

Keywords

aging, Alzheimer's/dementia, race/ethnicity, healthcare disparities, community

Manuscript received: June 29, 2021; **final revision received:** October 13, 2021; **accepted:** October 18, 2021.

Background

Older adults from underserved rural communities have fewer opportunities for early detection and diagnosis of Alzheimer's disease and related dementias (ADRD), in part due to barriers to provider-initiated dementia screenings. These barriers include a limited number of primary healthcare providers, shortage of specialists (e.g., neurologist, geriatric psychiatrists) limited availability to services for screening and referrals, time constraints in the office, uncertainty regarding benefits of dementia screening, fears of patient and family

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reactions, and patient dismissal or denial of symptoms (Fowler et al., 2015; Galvin, 2018; Galvin et al., 2020; Wiese et al., 2018).

Barriers to diminishing the threat of cognitive decline in rural settings have become more pronounced during the COVID-19 pandemic. Isolation, which was already an element which places older persons at risk for dementia, has been exacerbated by the pandemic-associated mandatory quarantines (MacLeod et al., 2021; Sepúlveda-Loyola et al., 2020). Opportunities for stimulation through social interaction have also decreased (Della Gatta et al., 2021). Researchers have pointed to the emergence or worsening of cognitive and neuropsychiatric symptoms in older adults with and without dementia as a result of the prolonged impact of COVID-19 restrictions (Suárez-González et al., 2021; Manca et al., 2020; Numbers & Brodaty, 2021). These studies suggest that the importance of detecting cognitive decline earlier is particularly urgent (Orgeta et al., 2019).

Increased Risk of ADRD among Underserved Groups

Although the U.S. Preventive Task Force concluded that there was insufficient evidence to conduct routine cognitive screenings, they did cite the benefits of early dementia detection, including advance care planning (Owens et al., 2020). Cognitive assessment is mandated in the Center for Medicare/Medicaid Services “annual wellness visit” for persons age 65 and older (Shaw, et al., 2014). However, uptake and utilization of annual wellness visits is low in most health systems; only about 20% of eligible older adults receive the annual wellness visit (Ganguli et al., 2018) and barriers to dementia screenings are heightened in underserved communities. African Americans and Hispanics have higher ADRD risks than Whites (Amjad et al., 2018; Mayeda et al., 2016), and rural residents face higher risks than urban dwellers (Matthews et al., 2019). In particular, rural farmworkers may be at increased risk of ADRD due to environmental exposures which increase ADRD risk, such as pesticides (Aloizou et al., 2020; Paul et al., 2018), chemicals (Berr & Letellier, 2020; Sabarwal et al., 2018), and particulate matter (Kilian & Kitazawa, 2018; Sullivan et al., 2021). Rural farmworkers often include high representation from racial or ethnic minority groups, which face added ADRD risk due to a complex range of factors that may include the chronic stressor of systemic racism (Williams, 2018; Zuelsdorff et al., 2020), lifestyle factors (Dixon & Chartier, 2016; James et al., 2017), and low socioeconomic status (Pega et al., 2017).

Benefits to Early Dementia Detection

Well-documented advantages of screening include identifying and addressing non-degenerative causes of cognitive decline, such as undiagnosed illnesses, mood disorders, medication mismanagement, and behavioral and mood modification (Galvin, 2018; Galvin et al., 2020). Persons who are aware of dementia risk can be informed of ways to slow cognitive

decline, such as improved control of cardiovascular disease and diabetes (Gottesman et al., 2017). Additional benefits of screening include prescription of medication to diminish symptoms and opportunities to participate in clinical trials testing new therapeutics. Accurate, early diagnosis of dementia could result in a cost savings of approximately \$8 trillion in related healthcare costs over the next 30 years (Gaugler et al., 2019).

Faith-based Approaches

To address this need for early dementia detection in rural underserved communities, our research has focused on increasing cognitive screening rates following educational outreach efforts. We previously examined basic knowledge of Alzheimer’s disease (BKAD; Wiese et al., 2017, 2019), stakeholder willingness to screen (Wiese, Williams, and Galvin, 2018, Wiese, Williams, Galvin, et al., 2020a, 2020b, 2020c), and rates of follow-through after referral after positive screens (Wiese, Williams, Galvin, et al., 2020a, 2020b, 2020c). We observed that faith-based settings are a potentially robust avenue in which dementia screening and educational programs can be successfully implemented.

As Schoenberg et al.’s (2009, 2012, 2016, 2017) Faith Moves Mountains (FMM) approach has resulted in numerous positive outcomes related to other chronic diseases in rural settings, we adapted the FMM model to develop a faith-based protocol to prompt early detection of cognitive impairment through screening and knowledge building. This FMM approach to ADRD detection was first tested in an urban Haitian Creole church (Daccarett et al., 2021), wherein 96% ($n = 50$ of 52) of eligible older adults invited participated in dementia education and memory screening. These prior in-person studies provided the foundation for the virtual approach to FMM as described in this paper.

Given social distancing requirements during the COVID-19 pandemic, the purpose of the current study was to test a telephone-based cognitive screening intervention among rural, underserved, and racially/ethnically diverse older adults. Our aims were to determine if conducting ADRD research activities with participants by telephone would result in 1) an increase in basic AD knowledge, 2) identifying potential AD risk through brief memory screenings, and 3) an increase in the number of completed referrals to primary care providers.

Methodology

Schoenberg et al.’s (2009, 2012, 2016, 2017) faith-based participatory model was applied in testing this virtual approach to increasing ADRD knowledge and cognitive screening rates. The FMM consists of several core elements, including (1) engaging faith leaders to assist in tailoring activities to meet the needs and values of the congregation (2) extensively training talented local community members to serve as faith-based health educators (FHE), and (3) incorporating local images, resources, and language to ensure cultural fit. Key to the

FMM model is the presence of and trust in and by local churches and project leadership's willingness to adhere to values and circumstances of these congregations. For example, FMM staff present the project protocols when the minister or other representatives consider the timing to be optimal. The FHEs are recruited from within each church and subsequently trained in providing educational and social support mechanisms to the study participants (Schoenberg et al., 2009, 2012, 2016). Due to the COVID-19 pandemic, the research protocol for the current study needed to shift to address safety concerns for our older adult population, who are critically vulnerable to the pandemic. The research team consulted with a community advisory board, comprised of community leaders and stakeholders. Following their suggestions, the FHE training was altered to videoconferencing, and treatment fidelity was assured. The FHE obtained audio-recorded informed consent, including an optional research registry consent. We made use of a telephone contact, with the FHE leading the singing of a hymn, sharing Bible verses regarding seeking knowledge and wisdom, and briefly discussing its application to health-seeking behaviors. The FHE administered sociodemographic and pre/post ADRD knowledge surveys, a brief educational intervention, and cognitive screening.

Setting

The research took place in Florida and was focused on a rural and underserved ethnically diverse community associated with the term "the Glades" surrounding Lake Okeechobee. The Glades is home to 58.4% African American and various Hispanic ethnicities (32.9%); Mexican, Puerto Rican, South and Central American, with field/farm work as the primary means of employment (United States Census Bureau, 2019). Florida has the second highest number of older adults in the country after California and second highest percentage after Maine, with more moving to the state annually. It is predicted that nearly 38% of FL residents who have ADRD are undiagnosed, with rates higher in rural counties (United States Census Bureau, 2019). Rural was defined for this work as all population or clusters not within an urbanized area (United States Census Bureau, 2019).

Design and Sample

To launch dementia education and screening during COVID-19 quarantine restrictions, an exploratory descriptive design using a convenience sample was chosen. Applying GPower 3.1 paired samples a-priori parameters of .5 medium effect size and 95% power, differences in pre-post BKAD knowledge scores were calculated, using the two-dependent means/matched pairs criteria (Faul et al., 2007). This resulted in a recommended sample size of 45, similar to the design of an earlier study conducted in a Haitian church ($n = 50$) (Daccarett et al., 2021).

Inclusion and Exclusion Criteria

Rural, community-dwelling adults age 50 and older who had not been previously diagnosed with AD were eligible to enroll in the study. This age group was selected because the risk of ADRD increases as age increases each decade (Fishman, 2017.) Participants needed to speak either English, Spanish, or Creole and had no plans to move from their respective area in the next 12 months to allow for a repeat screening at 1 year. Persons previously diagnosed with cognitive impairment, or persons under 50 were excluded from the investigative portion of the study, but were informed that an educational program would be started in person in the churches once quarantine restrictions were lifted. There were no age restrictions for the FHE or community advisory board members, but persons with education and experience in the health care or teaching field were those who primarily volunteered.

Informed Consent Documentation

To obtain virtual informed consent, the FHE either emailed, mailed, or read the consent to persons over the phone per the participant's language of preference, and then recorded the person's consent or refusal using either their cell phone or computer. If preferred, the participant could take a picture of the signed consents(s) and forward them, or mail back the documents. Participants were also asked if they wanted to sign a research registry consent to be considered for other studies related to ADRD. Each person was identified by an ID number during the recording. The name accompanying the number was kept on a secured computer in a separate file from the data files.

Recruitment of Churches, FHE, and Older adult Participants

Churches. The lead researcher originally met with members of the Glades Area Ministerial Association (GAMA) during their monthly meeting in October 2019 and explained the purpose and protocols of the study. Ten of the thirteen church leaders in attendance at the meeting signed up to learn more about the study. After reaching out to those ten, the lead researcher held virtual meetings with the five church leaders who were currently willing to continue with participation, even during the emerging COVID-19 pandemic, to explain the study protocols. The remaining five churches agreed to discuss the research further after the pandemic restrictions are eased. In the meetings with the GAMA leaders, the revised plan of conducting the telephone-based intervention with congregants was described.

Faith-based Health Educators

To select the FHE, we sought one member of each congregation who ideally held some experience in the field of

teaching, social work, health care, ministry, or other public service. The FHEs were bilingual (English-Spanish or English-Creole). The first 6 months of the project consisted of meetings with the community advisory board and GAMA to identify and enroll recommended FHE who responded to their pastor's invitation to participate. Of the six identified FHE candidates, one withdrew for personal reasons related to COVID-19. The remaining five FHE were computer literate with online access and were oriented easily to videoconferencing, which was used for the training sessions. Weekly virtual meetings were established after the FHE were trained in human subject protections. The FHE then completed an orientation to the study protocol, which included the study purpose and design, operational details, and HIPAA-compliant procedures. Discussion regarding their FHE role as the investigator's assistant were held. Next, the FHE completed all steps of the study as if they were participants, so they could easily describe the study procedures to the participants and answer questions. The FHE were also trained in basic information on ADRD, using resources from the [Hartford Institute of Geriatric Nursing \(2020\)](#), [National Institute of Aging \(2020\)](#), and [Alzheimer's Association \(2021\)](#). Teach-back methodology was employed to ascertain accuracy of FHE performance and make corrections as needed ([Yen & Leasure, 2019](#)).

Participants

Announcements about the study were made during virtual church services and included in written bulletins distributed to the congregations by mail and electronically. The five pastors reported that these written announcements would have reached a minimum of 85 persons age 50 or over (between 15 and 25 persons at each church). Church attendees were informed that they were welcome to contact the FHE directly by telephone or in the chat box during the church service videoconference if they were interested in participating. We limited our protocol for participants to strictly videoconferencing at the church, since many of the residents, who were retired farmworkers, did not own computers. Four of the churches hosted live stream services, which included the announcements about the study. One church broadcast their service and the study announcement over "Brother Church" radio, which is a popular medium for obtaining information in this population.

In addition to the required informed consent document, participants were invited to sign a second "research registry" consent regarding potential enrollment in future studies. Most ($n = 54$) of the 60 participants completed consent documents. After consenting, participants completed the sociodemographic survey and BKAD pre-test by telephone. As the pandemic prohibited the planned midweek or Sunday education sessions, the FHE reviewed and discussed the correct answers of the BKAD privately with each participant, with

emphasis regarding benefits of early detection and the modifiable risk factors. Then, the BKAD was readministered in a follow-up phone call two-three weeks later. The completion of all surveys and educational sessions took about 1 hour. If persons did not wish to participate at any stage of the study, we provided language-appropriate information sheets about ADRD. We also provided information regarding resources, including telehealth and virtual support groups at the primary investigator's University Memory and Wellness Center. Gift cards in the amount of \$10 were mailed to each person who consented to participate in the study, along with the information sheets.

Measures

All self-report study materials and measures were reviewed by the community advisory board and pilot tested for a) appropriateness of language, reading level, illustrations, and presentation of the educational materials, b) estimates of time required for implementation c) eliciting unanticipated barriers, and d) overall satisfaction with the process and materials. All measures were available in English, Creole, and Spanish.

Information was collected regarding age, sex, years lived rural, years of formal education, caregiver status (past or present), name of provider, prior memory testing, marital status, race/ethnicity, and previous dementia diagnosis and/or treatment (exclusionary criteria). In addition to the socio-demographic survey, two measures were used for data-collection via telephone. The Basic Knowledge of Alzheimer's Disease (BKAD) survey assessed AD knowledge, and the Mini-MoCA ([Nasreddine, 2019](#)) was used to assess cognitive performance.

The Mini-MoCA (T-Brief)

The 15-item Mini MoCA Telephone-brief ([Nasreddine, 2019](#)) was adapted from the earlier version of the Telephone MoCA (T-MoCA, [Pega et al., 2017](#)) based on the original MoCA ([Nasreddine et al., 2005](#)) of assessment for mild cognitive impairment. The MoCA-T (brief) 5-minute protocol total scores were highly correlated ($r = 0.87$; $p < 0.001$) with the MoCA scores ([Wong et al., 2015](#)). It differentiated between patients with executive domain impairment and those without impairment (area under ROC; 0.89 ; $p < 0.001$) with Cohen $d = 1.7$ group difference ([Masika et al., 2020](#)). The Mini MoCA-T (brief) requires about 5 minutes to complete and is comprised of tasks to allow for assessing different cognitive domains of attention, orientation, concentration, language, executive function, and memory. It can be administered by trained staff, but results should be evaluated by a trained health professional with cognitive expertise ([Nasreddine, 2019](#)). The range of possible scores is 0–15 with scores less than 11 suggesting cognitive impairment.

Table 1. Sociodemographics ($N = 61$).

	<i>M</i> (<i>SD</i>)	
Age	70.4	(8.3)
Education	11.0	(4.0)
Years rural	39.3	(25.5)
	<i>n</i>	%
African American	32	52.3
Afro Caribbean	7	11.7
Hispanic/Latino	3	5.0
White	17	28.3
Asian American	1	1.7
Female	46	75.1
Male	15	24.6
Could name provider	57	93.4
Single/separated/divorced	45	74.4
No previous memory check	53	86.9

The BKAD

The Basic Knowledge of Alzheimer's disease survey (BKAD) is a 30-item measure geared for underserved older adults with low education and health literacy levels. It has been tested in over 600 rural older adults, with a pre-post effect size of $r = 0.81$, indicating a large effect size (Lakens, 2013). However, tests for reliability and validity have been favorable, including Cronbach's alpha = .84 and overall Rasch item analysis of .94 (Wiese et al., 2017, 2020a, 2020b, 2020c, 2021).

The Brief Educational Intervention

After a participant completed the BKAD pre-test, the FHE immediately discussed each of their answers, and reviewed a basic information sheet with key points. The BKAD was administered again two-three weeks later, with another review of the answers and further discussion as needed after the post-test.

Data Analysis

All sociodemographic data, cognitive screening results, dementia-specific evaluations, follow-up appointments, and medical management were tracked and recorded in SPSS v25 (IBM, 2020). Continuous variable data included age, years living in a rural location, and years of formal education. Categorical data included sex, race/ethnicity, marital status, prior memory screening or caregiver experience, and dementia detection or treatment. Descriptive statistics were used to summarize sociodemographic characteristics and results of the completed Mini-MoCA and BKAD measures Paired samples t-tests were conducted to gauge learning between

pre-post test BKAD scores. Associations between sociodemographic variables and the outcomes of positive screening (Mini-MoCA scores below 11), and referral to providers were calculated using parametric Pearson/Spearman correlation coefficients. Due to the small sample size, we applied the Shapiro-Wilk test to test for normality of data. Linear regression models were performed to test if continuous sociodemographic predictor variables accounted for significant variance in the BKAD or Mini-MoCA scores.

Results

Sample Characteristics

Sixty of the 85 rural residents age 50 and over in attendance at church services during virtual recruitment announcements completed informed consent for engaging in the telephone-based study. As shown in Table 1, the majority (72%) of participants were non-white including African Americans (46.4%), Afro-Caribbeans (10.1%), Hispanics (4.2%), and Asian Americans (1.4%). Most (75%) were female. Over 90% were able to name their healthcare provider, but only eight (13.3%) reported previous testing for memory loss. Eighteen (22%) participants indicated that they had been a formal or informal caregiver for someone with dementia. The percentage of persons with Mini MoCA scores <11 who lived alone (72%) was almost twice that of persons who scored >11 (42%). Participants with Mini MoCA scores <11, indicating cognitive risk, showed a trend ($p = .17$; see Table 2) to have been a caregiver (46%), compared to those who scored >11 (32%).

Aim 1: Evaluating Changes in Basic AD Knowledge

Seventy-five percent of those who completed both the pre- and post-tests increased their BKAD score. Calculating the paired sample t-test with a possible maximum score of 30, the BKAD score indicated gains in knowledge, ($t(49) = -3.4$, $p < .001$) following the education intervention (pre: $M = 24.9$; $SD = 4.0$, and post: $M = 27.9$; $SD = 7.0$). Neither age, years lived in a rural area, or years of education correlated significantly with BKAD score. However, the Mini MoCA test for short-term memory (Recall) correlated moderately with the BKAD post-test ($r = .50$, $p = .01$).

Aim 2: Identifying Persons at Risk for Cognitive Decline

Of the 60 individuals who participated in the brief memory screening, 11 (18%) scored below 11 on the Mini-MoCA (Nasreddine, 2019), indicating the need for further evaluation (a positive screening result). Age was expected to act as a confounder, but in this cohort, results were not significant ($p = .061$) (Table 1). However, 10 of the 11 (91%) of those who needed referral were racially/ethnically diverse (African American/Hispanic/Afro-Caribbean). Those who lived alone

Table 2. Results of Alzheimer's disease knowledge tests (BKAD)¹ and Cognitive Screening (Mini-MoCA)².

Variable	Normal Cognition (<i>n</i> = 49)	Impaired Cognition (<i>n</i> = 11)	<i>p</i> value
BKAD pre-test ¹ (<i>M/SD</i>)	26.3 (3.6)	21.5 (5.1)	.001
BKAD post-test ¹ (<i>M/SD</i>)	27.3 (2.9)	22.8 (4.)	.006
Mini MoCA ² (<i>M/SD</i>)	12.3 (1.1)	9 (1.6)	.001
Can name provider, %	94.7	90	.214
Prior memory test, %	15.8	9.1	.094
Lives alone (<i>M/SD</i>)	42.1	72.7	.014
Prior AD caregiver (<i>M/SD</i>)	31.6	45.5	.165

(*p* = .01), and scored lower on the initial BKAD (*p* = .001) were also at greater risk for impaired cognition, as evidenced by the Mini-MoCA score <11 (see Table 2).

Aim 3: Evaluating Rates of Completed Referrals with Providers

The FHE conducted phone calls, and were successful in assuring that eight of the 11 participants completed follow-up provider appointments. Self-reports shared by participants three-six months after the study activities revealed that five patients were newly diagnosed with ADRD, and three reported no change in diagnosis or treatment.

Four additional findings emerged. First, we found that telephone-based recruitment was useful, with over 70% of eligible participants engaging in Alzheimer's disease education and memory screening. Second, 54 of 60 (90%) of participants signed the University's IRB-approved Research Registry consent to continue to engage in research. Third, cognitively impaired participants gained about the same amount of knowledge in pre-post test scores (1 point) as unimpaired participants. The items where gains in knowledge were the strongest involved finances. In the pretest, only 40% of persons answered correctly (true) for the item "Trouble managing bills may be a sign of Alzheimer's disease." Only 30% of persons answered correctly (true) for the item "Trouble counting change may be a sign of Alzheimer's disease", with increases in correct responses of 84% and 87%, respectively, in the pre-post test. These findings point to the need to assess knowledge at a community level, as knowledge gaps vary between settings. For example, in the BKAD surveys administered in Appalachian settings, the largest knowledge gaps were in the items "Wearing a heavy coat when it is hot outside may be a sign of AD" where only 59% answered correctly, and "Persons with a history of diabetes or high blood pressure are at greater risk of AD" with 61% answering correctly (Wiese et al., 2019). Fourth, the majority of those who screened positive (*n* = 11) did agree to follow-up with their provider (72%). Of those who did not follow-up within the 3-month time frame, the reasons given were "we don't want

to do anything about it, "we are fine the way we are", and "I'll talk to him [doctor] the next time I see him."

Discussion

We sought to evaluate the utility of using the telephone to conduct clinical, faith-based research with rural underserved participants. We also wanted to determine if providing ADRD information would be useful for increasing basic AD knowledge, identifying heightened AD risk, and increasing provider referrals when indicated, in a small, rural, older, ethnically diverse and largely farmworker (58%) cohort.

Researchers have previously shown that providing information regarding AD can increase AD knowledge in long-term care settings (Dassel et al., 2020) and in rural communities (Wiese et al., 2017, 2020a, 2020b, 2020c). Providing education regarding AD has been shown to increase racially/ethnically diverse faith-based participants in memory screenings (95%; Daccarett et al., 2021) and completed provider referrals (84–95%; Wiese et al., 2021). However, the current study contributes a new finding in that these same outcomes were achieved by engaging research participants over the phone in a rural, racially/ethnically diverse cohort during a pandemic. Moreover, diminishing the digital divide between rural and urban settings by increasing resources and training has emerged as a critical need during this pandemic, and will remain an urgent issue unless steps are taken to address the gap (Van Jaarsveld, 2020).

A unique finding in this sample is that a substantial number of farmworkers who were screened needed follow-up (64%), based on the Mini MoCA result. This relatively high rate of indication for referral may reflect the elevated-risk status of our target population and need to expand this study to other farmworker populations. It is important to note that farmworker families are often one of the most educationally disenfranchised and marginalized populations in the US. (According to the National Agricultural Workers 2015–2016 Survey (NAWS) only 51% of all farmworkers in the U.S. had work authorization, the average level of formal education completed by farmworkers was eighth grade, and the mean household income was between \$20,000 and \$24,999. These factors can result in limited opportunities, including challenges that lead to poor upward mobility and lower quality

and level of education. Low education has been identified as an independent risk factor for cognitive decline in late life. A systematic review recently showed that education reduces the risk of ADRD cognitive decline (Clouston et al., 2020). Researchers suggest that education may play a role in predicting delayed onset of accelerated cognitive decline. The implications for cognitive reserve suggest that education promotes resilience to brain changes associated with dementia, such that the reserve effect of education protects against early decline, but reserve is more depleted in highly educated individuals once clinical symptoms are present. If COVID-19-associated isolation continues to exacerbate the disparity of opportunities for engaging rural, ethnically diverse older adults in continuing education opportunities, the telephone may be a means for offering brief learning activities as a way to maintain engagement and continue screening folks during times of isolation.

Limitations

We acknowledge several limitations, including the small, self-selected sample and the lack of a control condition. The reliability and validity of the Mini-MoCA method of cognitive assessment needs further study, as it is a novel instrument. There were requests from participants for some type of visual aids such as pictures or a video instead of an auditory approach. Consequently, a visual hand-out from the NIA was later mailed to the participant as a take-home information sheet, along with a copy of the BKAD Key (correct answers).

Results of follow-up with providers relied on participant self-report. Although three of the eight participants scoring as cognitively impaired may not have had a change in diagnosis or treatment, these results may not be accurate. It is also unknown what the providers' comfort or knowledge levels are in regards to ADRD detection, diagnosis, and management. These are areas to improve for future research.

Conclusion

The telephone is the primary means of communication among this underserved community where only 45% of the entire population have broadband internet access (United States Census Bureau, 2019). The use of the telephone was particularly successful in maintaining participation of rural older adults in the current study. Future considerations include the need to further evaluate the effectiveness of telephone approaches for increasing dementia awareness, detection, and management in quarantine situations. It is important to continue including more rural and diverse samples in registries or research on cognition. Disease progression and treatments may vary among groups, but to what extent is unknown, due to low representation in studies (Glymour & Whitmer, 2019). It is also important in rural settings to continue fidelity through sustained presence, offer culturally

relevant faith-based health promotion programs, and provide opportunities for engagement in research activities.


Declaration of conflicting interests

The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

Funding

The author(s) disclosed receipt of the following financial support for the research, authorship, and/or publication of this article: This study is supported by National Institutes of Aging (K01AG064047).

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References

- Aloizou, A. M., Siokas, V., Vogiatzi, C., Peristeri, E., Docea, A. O., Petrakis, D., & Dardiotis, E. (2020). Pesticides, cognitive functions and dementia: A review. *Toxicology Letters*, 326(15 June), 31-51. <https://doi.org/10.1016/j.toxlet.2020.03.005>. PMID: 32145396.
- Alzheimer's Association. (2021). *Alzheimer's Education Center*. Clinical Education. <https://training.alz.org/ClinicalEducation>.
- Amjad, H., Roth, D. L., Sheehan, O. C., Lyketsos, C. G., Wolff, J. L., & Samus, Q. M. (2018). Underdiagnosis of dementia: An observational study of patterns in diagnosis and awareness in US older adults. *Journal of General Internal Medicine*, 33(7), 1131-1138. <https://doi.org/10.1007/s1160>.
- Berr, C., & Letellier, N. (2020). Occupational determinants of cognitive decline and dementia. *Handbook of Disability, Work and Health*, (30 July), 235-249. https://doi.org/10.1007/978-3-030-24334-0_11.
- Clouston, S. A., Smith, D. M., Mukherjee, S., Zhang, Y., Hou, W., Link, B. G., & Richards, M. (2020). Education and cognitive decline: An integrative analysis of global longitudinal studies of cognitive aging. *The Journals of Gerontology: Series B*, 75(7), e151-e160. <https://doi.org/10.1093/geronb/gbz053>.
- Daccarett, S., Wiese, L., & Ordóñez, M. (2021). A faith-based approach to increasing alzheimer's disease knowledge, cognitive screening, and referrals among older haitian Americans. *Journal of Community Health Nursing*, 38(2), 103-119. <https://doi.org/10.1080/07370016.2021.1887566>.
- Dassel, K., Butler, J., Telonidis, J., & Edelman, L. (2020). Development and evaluation of Alzheimer's Disease and related dementias (ADRD) best care practices in long-term care online training program. *Educational Gerontology*, 46(3), 150-157. <https://doi.org/10.1080/03601277.2020.1717079>.
- Della Gatta, F., Terribili, C., Fabrizi, E., & Moret-Tatay, C. (2021). Making Older Adults' Cognitive Health Visible After Covid-19 Outbreak. *Frontiers in Psychology*, 12(14 June), 648208. <https://doi.org/10.3389/fpsyg.2021.648208>.
- Dixon, M. A., & Chartier, K. G. (2016). Alcohol use patterns among urban and rural residents: demographic and social influences. *Alcohol Research: Current Reviews*, 38(1), 69.

- Faul, F., Erdfelder, E., Lang, A.-G., & Buchner, A. (2007). G*Power 3: A flexible statistical power analysis for the social, behavioral, and biomedical sciences. *Behavior Research Methods*, 39(2), 175–191. <https://doi.org/10.3758/bf03193146>.
- Fishman, E. (2017). Risk of developing dementia at older ages in the United States. *Demography*, 54(5), 1897–1919. <https://doi.org/10.1007/s13524-017-0598-7>.
- Fowler, N. R., Perkins, A. J., Turchan, H. A., Frame, A., Monahan, P., Gao, S., & Boustani, M. A. (2015). Older primary care patients' attitudes and willingness to screen for dementia. *Journal of Aging Research*. <http://dx.doi.org/10.1155/2015/4232>.
- Galvin, J. E. (2018). Using informant and performance screening methods to detect mild cognitive impairment and dementia. *Current Geriatrics Reports*, 7(1), 19–25. <https://doi.org/10.1007/s13670-018-0236-2>.
- Galvin, J. E., Tolea, M. I., & Chrisphonte, S. (2020). What older adults do with the results of dementia screening programs. *Plos One*, 15(7), e0235534. <https://doi.org/10.1371/journal.pone.0235534>.
- Ganguli, I., Souza, J., McWilliams, J. M., & Mehrotra, A. (2018). Practices caring for the underserved are less likely to adopt Medicare's annual wellness visit. *Health Affairs*, 37(2), 283–291. <https://doi.org/10.1377/hlthaff.2017.1130>.
- Gaugler, J., James, B., Johnson, P. M., Marin, A., & Weuve, J. (2019). Alzheimer's association report. 2019 Alzheimer's disease facts and figures. *Alzheimer's & Dementia*, 15(3), 321–387. <https://doi.org/10.1016/j.jalz.2019.01.010>.
- Glymour, M. M., & Whitmer, R. A. (2019). Using cross-cultural studies to improve evidence on dementia prevention: Lessons from the special issue sponsored by the International Research Network on Dementia Prevention (IRNDP). *Journal of Alzheimer's Disease*, 70(Suppl 1), S5. <https://doi.org/10.3233/JAD-190304>.
- Gottesman, R. F., Albert, M. S., Alonso, A., Coker, L. H., Coresh, J., Davis, S. M., Deal, J. A., McKhann, G. M., Mosley, T. H., Sharrett, A. R., Schneider, A., Windham, B. G., Wruck, L. M., & Knopman, D. S. (2017). Associations between midlife vascular risk factors and 25-year incident dementia in the atherosclerosis risk in communities (aric) cohort. *JAMA Neurology*, 74(10), 1246–1254. <https://doi.org/10.1001/jamaneurol.2017.1658>.
- Hartford Institute of Geriatric Nursing and Consortium of New York Geriatric Education Centers (2020) Dementia and collaborative care. *E-learning module*. Retrieved from <https://hign.org/consultgeri-resources/elearning>.
- James, C. V., Moonesinghe, R., Wilson-Frederick, S. M., Hall, J. E., Penman-Aguilar, A., & Bouye, K. (2017). Racial/Ethnic Health Disparities Among Rural Adults - United States, 2012-2015. *Morbidity and Mortality Weekly Report. Surveillance Summaries (Washington, D.C.: 2002)*, 66(23), 1–9. <https://doi.org/10.15585/mmwr.ss6623a1>.
- Kilian, J., & Kitazawa, M. (2018). The emerging risk of exposure to air pollution on cognitive decline and Alzheimer's disease—evidence from epidemiological and animal studies. *Biomedical journal Chang Gung University*, 41(3), 141–162. <https://doi.org/10.1016/j.bj.2018.06.001>.
- Lakens, D. (2013). Calculating and reporting effect sizes to facilitate cumulative science: A practical primer for t-tests and ANOVAs. *Frontiers in Psychology*, 4, 863. <https://doi.org/10.3389/fpsyg.2013.00863>.
- MacLeod, S., Tkatch, R., Kraemer, S., Fellows, A., McGinn, M., Schaeffer, J., & Yeh, C. S. (2021). COVID-19 Era social isolation among older adults. *Geriatrics*, 6(2), 52. <https://doi.org/10.3390/geriatrics6020052>.
- Manca, R., De Marco, M., & Venneri, A. (2020). The impact of COVID-19 infection and enforced prolonged social isolation on neuropsychiatric symptoms in older adults with and without dementia: A review. *Frontiers in Psychiatry*, 11(20 Oct), 1086. <https://doi.org/10.3389/fpsyg.2020.585540>. PMID: 33192732 PMCID: PMC7649825.
- Masika, G. M., Yu, D. S., Li, P. W., Wong, A., & Lin, R. S. (2020). Psychometrics and diagnostic properties of the montreal cognitive assessment 5-min protocol in screening for mild cognitive impairment and dementia among older adults in tanzania: A validation study. *International Journal of Older People Nursing*, 16, e12348. <https://doi.org/10.1111/opn.12348>.
- Matthews, K. A., Xu, W., Gaglioti, A. H., Holt, J. B., Croft, J. B., Mack, D., & McGuire, L. C. (2019). Racial and ethnic estimates of Alzheimer's disease and related dementias in the United States (2015–2060) in adults aged ≥ 65 years. *Alzheimer's & Dementia*, 15(1), 17–24. <https://doi.org/10.1016/j.jalz.2018.06.3063>.
- Mayed, E. R., Glymour, M. M., Quesenberry, C. P., & Whitmer, R. A. (2016). Inequalities in dementia incidence between six racial and ethnic groups over 14 years. *Alzheimer's & Dementia*, 12(3), 216–224. <https://doi.org/10.1016/j.jalz.2015.12.007>.
- Nasreddine, Z. (2019). *Remote MoCA testing*. Retrieved from <https://www.mocatest.org/faq/>.
- Nasreddine, Z. S., Phillips, N. A., Bédirian, V., Charbonneau, S., Whitehead, V., Collin, I., & Chertkow, H., ... (2005). The montreal cognitive assessment, MoCA: A brief screening tool for mild cognitive impairment. *Journal of the American Geriatrics Society*, 53(4), 695–699. <https://doi.org/10.1111/j.1532-5415.2005.53221.x>Citations: 7.
- National Institute of Aging (2020). *Health Information: Alzheimer's disease and related dementias*. National Institute of Aging. Retrieved from <https://www.nia.nih.gov/health/alzheimers>.
- Numbers, K., & Brodaty, H. (2021). The effects of the COVID-19 pandemic on people with dementia. *Nature Reviews. Neurology*, 17(2), 69–70. <https://doi.org/10.1038/s41582-020-00450-z>.
- Orgeta, V., Mukadam, N., Sommerlad, A., & Livingston, G. (2019). The lancet commission on dementia prevention, intervention, and care: A call for action. *Irish Journal of Psychological Medicine*, 36(2), 85–88. <https://doi.org/10.1017/ipm.2018.4>.
- Owens, D. K., Davidson, K. W., Krist, A. H., Barry, M. J., Cabana, M., Caughey, A. B., & Wong, J. B. (2020). Screening for cognitive impairment in older adults: US preventive services task force recommendation statement. *JAMA*, 323(8), 757–763. <https://doi.org/10.1001/jama.2020.0435>.
- Paul, K.C., Jerrett, M., & Ritz, B. (2018). Type 2 diabetes mellitus and alzheimer's disease: Overlapping biologic mechanisms and environmental risk factors. *Curr Envir Health Rpt*, 5(1), 44–58. <https://doi.org/10.1007/s40572-018-0176-1>.

- Pega, F., Valentine, N. B., Rasanathan, K., Hosseinpoor, A. R., Torgersen, T. P., Ramanathan, V., ..., & Neira, M. P. (2017). The need to monitor actions on the social determinants of health. *Bulletin of the World Health Organization*, 95(11), 784. <https://doi.org/10.1016/j.amjms.2016.01.008>.
- Sabarwal, A., Kumar, K., & Singh, R. P. (2018). Hazardous effects of chemical pesticides on human health—Cancer and other associated disorders. *Environmental Toxicology and Pharmacology*, 63(October), 103–114. <https://doi.org/10.1016/j.etap.2018.08.018>. PMID: 30199797.
- Schoenberg, N. E., Ciciurkaite, G., & Greenwood, M. K. (2017). Community to clinic navigation to improve diabetes outcomes. *Preventive Medicine Reports*, 5, 75–81. <https://doi.org/10.1016/j.pmedr.2016.11.015>.
- Schoenberg, N. E., Eddens, K., Jonas, A., Snell-Rood, C., Studts, C. R., Broder-Oldach, B., & Katz, M. L. (2016). Colorectal cancer prevention: Perspectives of key players from social networks in a low-income rural US region. *International Journal of Qualitative Studies on Health and Well-Being*, 11(1), 30396. <https://doi.org/10.3402/qhw.v11.30396>.
- Schoenberg, N. E., Hatcher, J., Dignan, M. B., Shelton, B., Wright, S., & Dollarhide, K. F. (2009). Faith moves mountains: An appalachian cervical cancer prevention program. *American Journal of Health Behavior*, 33(6), 627–638. <https://doi.org/10.5993/ajhb.33.6.1>.
- Schoenberg, N. E., Howell, B. M., & Fields, N. (2012). Community strategies to address cancer disparities in Appalachian Kentucky. *Family & Community Health*, 35(1), 31. <https://doi.org/10.1097/FCH.0b013e3182385d2>.
- Sepúlveda-Loyola, W., Rodríguez-Sánchez, I., Pérez-Rodríguez, P., Ganz, F., Torralba, R., Oliveira, D. V., & Rodríguez-Mañas, L. (2020). Impact of social isolation due to COVID-19 on health in older people: Mental and physical effects and recommendations. *The Journal of Nutrition, Health & Aging*, 24(9), 938–947. <https://doi.org/10.1007/s12603-020-1469-2>.
- Shaw, F. E., Asomugha, C. N., Conway, P. H., & Rein, A. S. (2014). The Patient Protection and Affordable Care Act: opportunities for prevention and public health. *Lancet*, 384(9937), 75–82. [https://doi.org/10.1016/S0140-6736\(14\)60259-2](https://doi.org/10.1016/S0140-6736(14)60259-2).
- Suárez-González, A., Rajagopalan, J., Livingston, G., & Alladi, S. (2021). The effect of Covid-19 isolation measures on the cognition and mental health of people living with dementia: a rapid systematic review of one year of evidence. *medRxiv*, 39(31 July). <https://doi.org/10.1101/2021.03.17.21253805>. PMID: 34386758 PMCID: PMC8342894.
- Sullivan, K. J., Ran, X., Wu, F., Chang, C. C. H., Sharma, R., Jacobsen, E., & Ganguli, M. (2021). Ambient fine particulate matter exposure and incident mild cognitive impairment and dementia. *Journal of the American Geriatrics Society*. <https://doi.org/10.1111/jgs.17188>. Web Early View
- United States Census Bureau (2019). *US Census*. Bureau QuickFacts. Retrieved from <https://www.census.gov/quickfacts/bellegladecityflorida>.
- Van Jaarsveld, G. M. (2020). The effects of COVID-19 among the elderly population: a case for closing the digital divide. *Frontiers in Psychiatry*, 11. <https://doi.org/10.3389/fpsy.2020.577427>.
- Wiese, L.A., Hicken, B., & Weaver, R. (2018). Exploring barriers to service use among older rural residents. *Innovation in Aging*, 2(suppl 1), 867. <https://doi.org/10.1093/geroni/igy023.3238>.
- Wiese, L., Williams, C.L., & Galvin, J.E. (2018). Ethnically diverse rural Florida stakeholder perceptions about cognitive screening. *Journal of Aging & Mental Health*, 23(12), 1616–1628. <https://doi.org/10.1080/13607863.2018.1525607>.
- Wiese, L.K., Williams, C.L., Newman, D., & Tappen, R. M. (2019). An updated measure of alzheimer's disease knowledge for use in underserved rural settings. *Journal of Aging and Mental Health*, 24(8), 1348–1355. <https://doi.org/10.1080/13607863.2019.1584880>.
- Wiese, L. K., Williams, C. L., Tappen, R., Newman, D., & Rosselli, M. (2017). Assessment of basic knowledge about Alzheimer's disease among older rural residents: A pilot test of a new measure. *Journal of Nursing Measurement*, 25(3), 519–548. <https://doi.org/10.1891/1061-3749.25.3.519>.
- Wiese, L.K., Lingler, J., Williams, I.C., Schoenberg, N.E., & Galvin, J.E. (2020a). Engaging rural older minority adults in dementia research during a pandemic-associated quarantine: Developing topics. *Alzheimer's & Dementia*, 16, e047225. <https://doi.org/10.1002/alz.047225>.
- Wiese, L.K., Williams, C.L., Hain, D., Newman, D., Houston, C.P., Kaack, C., & Galvin, J.E. (2020b). Detecting dementia among older, ethnically diverse residents of rural subsidized housing. *Journal of Geriatric Nursing*, 42(2), 524–532. <https://doi.org/10.1016/j.gerinurse.2020.09.005>. [Epub ahead of print] PubMed PMID: 33039199
- Wiese, L., Williams, I., Williams, C.L., & Galvin, J.E. (2020c). Discerning rural appalachian stakeholders' attitudes toward memory screening. *Journal of Aging and Mental Health*, 25, 797–806. doi: 10.1080/13607863.2020.1725739.
- Wiese, L., Williams, I., Schoenberg, N.E., Galvin, J.E., & Lingler, J. (2021). AAIC Satellite Conference: Promoting Diverse Perspectives: Addressing Health Disparities Related to Alzheimer's and All Dementias. Virtual. Poster #57350: Changes in Alzheimer's Disease Knowledge and Screening in a Rural, Diverse Community After a Faith-Based Intervention, Denver, CO, 14 June 2021.
- Williams, D. R. (2018). Stress and the mental health of populations of color: advancing our understanding of race-related stressors. *Journal of Health and Social Behavior*, 59(4), 466–485. <https://doi.org/10.1177/0022146518814251>.
- Wong, A., Nyenhuis, D., Black, S. E., Law, L. S., Lo, E. S., Kwan, P. W., & Mok, V. (2015). Montreal Cognitive Assessment 5-minute protocol is a brief, valid, reliable, and feasible cognitive screen for telephone administration. *Stroke*, 46(4), 1059–1064. <https://doi.org/10.1161/STROKEAHA.114.007253>Stroke.
- Yen, P. H., & Leasure, A. R. (2019). Use and effectiveness of the teach-back method in patient education and health outcomes. *Federal Practitioner*, 36(6), 284. <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6590951/>.
- Zuelsdorff, M., Okonkwo, O. C., Norton, D., Barnes, L. L., Graham, K. L., Clark, L. R., ..., & Gleason, C. E. (2020). Stressful life events and racial disparities in cognition among middle-aged and older adults. *Journal of Alzheimer's Disease*, 73(2), 671–682. <https://doi.org/10.3233/JAD-190439>.