Older Adults’ Attitudes towards Cognitive Testing: Moving towards Person-Centeredness

Sara Wong    Claudia Jacova
Pacific University, Hillsboro, OR, USA

Keywords
Cognitive testing · Person-centered care · Attitudes · Preferences · Willingness

Abstract

Background: Research on person-centered cognitive testing is beginning to emerge. The current study is the first to focus on eliciting concrete preferences around the test experience. Methods: Adults ≥50 years old completed the Attitudes Around Cognitive Testing (AACT) questionnaire on mturk.com. AACT elicits preferences for cognitive tests, the importance attributed to having choices, and willingness to engage in testing. Results: Data are reported for 289 respondents. The proportion of participants expressing preferences varied by domain (modality [49.5%), location [47.2%), company [80.1%), result delivery [78.3–89.7%]). Importance ratings for all domains had a median of 4 and a range of 1–5 using a Likert scale of agreement. Most participants (85.5%) were willing to engage in testing. Conclusion: Older adults have preferences for cognitive tests, especially with delivery of results.

Introduction

The importance of detecting cognitive impairment in older adults during primary care annual wellness visits has been recognized by gerontology and geriatrics experts [1], stakeholder associations [2], and policy makers [2, 3]. Despite this, more than 50% of persons with dementia have never received a diagnosis from a physician [4]. Currently, the detection of cognitive impairment and dementia is based on case finding. Screening is initiated by clinician’s suspicion, and a diagnosis is made after the clinician conducts further tests or refers the patient for imaging and full diagnostic assessment [5]. A survey of primary care providers

Claudia Jacova
Pacific University
190 SE 8th Ave Suite 181
Hillsboro, OR 97123 (USA)
E-Mail cjacova@pacificu.edu

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Published by S. Karger AG, Basel
www.karger.com/dee

Original Research Article

Dement Geriatr Cogn Disord Extra 2018;8:348–359
DOI: 10.1159/000493464
Received: June 4, 2018
Accepted: September 2, 2018
Published online: October 9, 2018

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Claudia Jacova
Pacific University
190 SE 8th Ave Suite 181
Hillsboro, OR 97123 (USA)
E-Mail cjacova@pacificu.edu
found that following suspicion of cognitive impairment, the majority of physicians conduct medical tests to exclude underlying causes, assess for depression and daily functioning, and perform a mental status test [6]. A systematic review and meta-analysis by Tsoi et al. [7] revealed large variations in the use of mental status tests physicians use to aid in the detection cognitive impairment; 11 screening tests were identified, ranging in administration time from 5 to 20 min, and varying in cognitive domains measured. For example, the widely used Mini-Mental State Examination measures orientation, memory, language, attention, and visuospatial abilities, while the Mini-Cog measures memory, visuospatial, and executive functioning.

Despite the recognized importance of detecting cognitive impairment in older adults, it is often missed in primary care [8]. Factors related to missed and delayed diagnosis of dementia in medical settings fall into four categories: physician, system-related, caregiver, and patient factors. Physician and system-related factors involve communication problems between the physician and patient and limited appointment time [9]. Caregiver factors include preferences towards not knowing the patients’ condition [9, 10]. Patient factors include older patient age, being unmarried, and having lower levels of education [9]. Patient refusal to be assessed or to be treated if diagnosed is also a commonly cited barrier. More than one-third (37.7%) of older primary care patients in one recent study refused diagnostic screening [11]. In another study, approximately half (47.7%) of the primary care patients who screened positive for dementia refused full diagnostic assessment [12]. Patient characteristics associated with the refusal of screening or follow-up diagnostic assessment include the absence of subjective concern of cognitive symptoms [12], living alone, and reported distress about the possibility of being diagnosed with dementia [13]. The subjective experience of cognitive testing is also important in assessing older adults’ participation in screening and the diagnostic process. Older adults have described cognitive tests as stressful, bewildering, and embarrassing [4, 14]. They may perceive tests as a threat to their dignity and self-respect [14]. The subjective experience of distress related to cognitive testing may also be a function of increasing cognitive impairment, and predictors of distress may be related to patient awareness about test difficulty and performance [15].

To date, few studies have investigated how to reduce patient-level barriers to dementia detection. Research utilizing a person-centered approach to overcome such barriers is an unmet need. In person-centered care, healthcare providers explore patients’ preferences and attitudes around their care, and also provide them with information to help them make decisions regarding diagnostic and therapeutic interventions [16, 17]. Preferences are viewed as a “tendency to consider something desirable or undesirable” [18] and attitudes are a “set of beliefs, feelings, and behavioral tendencies towards a socially significant event or object” [19]. Research on person-centered care provides evidence that such an approach to healthcare improves objective and subjective health outcomes [20]. The core features of person-centered care include exploring patient preferences and increasing patient autonomy to promote self-control and self-efficacy [21, 22], and to enable more effective participation in the healthcare system [23].

Attaining person-centered care may be particularly important for older adults given this population’s heterogeneity in health and level of functioning, personal treatment preferences, and individual goals. A recent study found that older adults prefer to participate actively in healthcare decisions [24]. More understanding is needed regarding how older adults can be empowered to engage in their healthcare decisions. In the context of cognitive testing, one approach to person-centered testing may include inviting older adults to make choices regarding their experience (e.g., where they take the test, who would be with them during the test, the modality in which the test is taken, how they receive their results). In turn, such choices may lead to greater acceptance of the cognitive test experience and its results.
The goal of the present study was to elicit older adults’ attitudes and preferences towards cognitive testing. The Attitudes Around Cognitive Testing (AACT) questionnaire was developed specifically for the current study to identify attitudes and preferences regarding cognitive testing in the context of a visit with one’s primary care physician. Our aim was to characterize older adults’ preferences regarding the cognitive test experience, and to probe the importance they attach to making choices according to their preferences. We also examined the association between importance ratings and willingness to undergo cognitive testing. We hypothesized that older adults will value having choices regarding the cognitive test experience. We also hypothesized that older adults will be more willing to undergo cognitive testing if they can choose the circumstances of their test experience.

Methods

The methods are reported in accordance with the Checklist for reporting Results of Internet Surveys [25].

Participants

Adults 50 years or older and fluent in English were recruited through an online crowdsourcing site, Amazon Mechanical Turk (www.mturk.com). Amazon's Mechanical Turk is a web-based market where requesters post jobs and workers choose which jobs to do for pay. Workers on Mechanical Turk browse amongst existing jobs and are not under any obligation to complete particular tasks. Initial contact with eligible participants was made online. Data collection relied on an open survey format, allowing any potential respondents who met eligibility criteria to voluntarily partake in the study. Accordingly, AACT was not particularly promoted to eligible respondents. Eligibility criteria for MTurk users required participants to (1) be registered on MTurk with a birthdate before 1967 to ensure age requirements were met (at least 50 years of age), (2) be geographically located in the United States, and (3) have provided valid, acceptable data on at least 95% of previously competed MTurk surveys/tasks. Before consenting to the study, respondents were informed of the purpose of the study, the risks and benefits of the research, and the contact information to study personnel should they experience problems or concerns in the course of participating in the study. Due to the anonymous nature of the questionnaire, no identifying information was collected or stored. Before submitting responses, respondents were able to review and change their answers. Only one response per IP address was accepted. Upon completion of the questionnaire, participants were paid USD 1. Data were collected from December 2017 through January 2018, concluding once 300 responses were collected.

The study received approval from the Pacific University Institutional Review Board.

Measures

AACT items captured sociodemographic and background characteristics, personal preferences around cognitive tests, importance of being given choices around the cognitive test experience, and willingness to undergo cognitive testing. We developed AACT items based on multiple studies that have elicited patients’ attitudes and preferences in the context of their medical care [17, 26–29]. We focused on preferences in five domains of the cognitive test experience: (1) modality, (2) location, (3) company, (4) result delivery for negative results (cognitive test indicates no changes in the participants’ memory or thinking), and (5) result delivery for positive results (cognitive test indicates changes in the participants’ memory or thinking). In order to assess the value of being given choices in relation to participants’ preferences, we used the term “importance of choosing” throughout AACT. Finally, we evaluated
participants' willingness to undergo cognitive testing drawing on existing measures and attitudinal surveys of dementia screening [10, 30]. The response format varies throughout AACT, including 5-point Likert scale of agreement, binary choices of yes or no, and selecting all options that apply. Throughout AACT, we used the term Alzheimer's disease as opposed to dementia because previous work by Boustani et al. [10] suggested that "Alzheimer's disease" is more readily understood. We provided participants with the general context of taking a test that measures memory and thinking with their doctor and asked them about their thoughts and feelings. We decided to avoid distinguishing between different types of cognitive tests (e.g., cognitive screening tests, neuropsychological testing) to eliminate potential confusion among respondents. Sample items illustrating our three primary constructs of preferences, importance, and willingness are provided in Table 1. The instructions provided to orient respondents to the context of the survey are also shown in Table 1.

Table 1. Examples of items in AACT evaluating primary outcomes of preferences, importance of choice, and willingness to undergo cognitive testing

Introduction to AACT to orient respondents
"The purpose of the project is to understand your thoughts regarding taking tests of memory and thinking with your doctor. We are interested in developing a person-centered approach of monitoring changes in memory and thinking that can be used in primary care settings... The following questions ask about your feelings towards taking tests that would measure your memory and thinking. Some problems with memory and thinking may be normal; others may indicate a serious condition. Tests that can detect changes in memory and thinking often help doctors detect a serious condition in its early stage."

Preferences regarding the cognitive test experience
Participants were asked to select all choices that applied after reading first-person statements. e.g., Modality: "I would want to take the test using..."
Response categories included:
- Paper-and-pencil
- A computer
- A mobile device (iPad, tablet, phone)

Importance of being given choices regarding the cognitive test experience
Participants read first-person statements and were asked to report their agreement using a 5-point Likert scale. e.g., Modality: "It is important to me that my doctor lets me choose how I take the test, either through pencil-and-paper, computer, or mobile device."

Willingness to undergo cognitive testing
Participants read first-person statements and were asked to report their agreement using a 5-point Likert scale. e.g., "If my doctor asked me to take a test to detect changes in my memory and/or thinking today, I would be willing to take it."

Statistical Analysis
Participants' preferences were captured in a "select all that apply format," and coded into different categories. Those in the "No preference category" selected only "I have no preferences," and no other response. Those in a "Single preference" category endorsed one specific preference respective to the cognitive test domain in question. Those in the "Multiple preference" category endorsed more than one preference. Finally, we coded invalid responses as those that endorsed "I have no preferences" and one or more specific preferences, and excluded invalid responses from our analyses. For additional analyses, preferences responses were recoded a second time to reflect a dichotomous preference variable, differentiating between those who endorsed preferences and those who did not endorse preferences. Participants' Likert-scale ratings were reported with median and range as measures of central tendency and variability, as recommended by Sullivan and Artino [31]. Willingness was
modeled as a binary variable: Willing included those that strongly agreed or agreed to undergoing testing; Not willing included those that were neutral, disagreed or strongly disagreed.

All statistical analyses were performed with SPSS statistical software (25.0.0.0). The statistical significance was assumed at $p < 0.05$. We used the $\chi^2$ test to assess whether dichotomized preference responses (any or no preference) were associated with person characteristics including gender, age, education level, and subjective cognitive concern. We used nonparametric Mann-Whitney U tests to identify associations between importance ratings and the categorical person characteristics. We used binary logistic regression to examine the associations between willingness to undergo cognitive testing, preferences, and importance ratings.

Results

Participant Characteristics

All submitted questionnaires were completed. Data were available for 300 respondents and analyzed for 289 participants who completed AACT. Individuals who endorsed a previous diagnosis of a neurocognitive disorder were excluded from our analyses. Missing data were excluded from analyses at the item level. No clear pattern of missing data emerged. Participant characteristics are provided in Table 2. The overall age of participants ranged from 50 to 80 at the time of survey completion (mean = 63 years), with the majority being between 50 and 65 years of age (69%). Most participants were female (66.7%) and White (90.4%). Nearly half of the participants did not have a college degree (51.9%) and were not married (51.5%). More than half of the participants endorsed subjective cognitive concern (63.2%). Most of our respondents reported no previous experience with cognitive tests (89.4%), and/or no diagnosis of neurocognitive disorder (99%).

| Table 2. Characteristics of study participants who completed online versions of AACT |
|---|
| **Age, years** |
| Mean ± SD | 63±4.8 |
| **Gender** |
| Male | 98 (33.3%) |
| Female | 196 (66.7%) |
| **Race** |
| Caucasian | 265 (90.4%) |
| African-American | 18 (6.1%) |
| Other/multiracial | 7 (2.3%) |
| **Marital status** |
| Married | 143 (48.5%) |
| Not married | 152 (51.5%) |
| **Educational attainment** |
| ≤High school | 33 (11.2%) |
| Some college | 120 (40.7%) |
| College or beyond | 142 (48.1%) |
| **Concern of cognitive impairment** |
| Endorsed | 187 (63.2%) |
| Not endorsed | 109 (36.8%) |
| **Previous experience with cognitive tests** |
| Endorsed | 31 (10.6%) |
| Not endorsed | 262 (89.4%) |
| **Previous diagnosis of neurocognitive disorder** |
| None | 297 (99.0%) |
| Mild cognitive impairment | 1 (0.3%) |
| Alzheimer’s disease | 2 (0.7%) |
Preferences regarding the Cognitive Test Experience

Participants’ preferences regarding the five domains of the cognitive test experience are presented in Table 3. The proportion of participants expressing preferences varied by domain and ranged from 49.5% for modality to 89.7% for delivery of concerning results. The most frequently endorsed single preferences were to take the test on a computer or a mobile device (27.0%), at home (33.4%), and alone (62.5%), for modality, location, and company, respectively. Most participants had preferences regarding result delivery. The most frequently endorsed singular preference was a telephone call (17.9%) for receiving negative (normal) results, and through an office visit with their physician for positive (concerning) results (32.4%).

Female gender and subjective cognitive concern were associated with a higher proportion of those endorsing preferences. Specifically, women tended to report having more prefer-
ences for how they receive negative results (women: 55.0%, men: 23.5%, $\chi^2[1, n = 251] = 4.02, p < 0.05$) and positive results (women: 62.7%, men: 26.9%; $\chi^2[1, n = 260] = 5.26, p < 0.05$) than men. Those with subjective cognitive concerns reported having preferences more than those without concerns for the delivery of positive results only (subjective concern: 58.4%, no subjective concern: 31.3%; $\chi^2[1, n = 262] = 4.43, p < 0.05$).

**Importance of Being Given Choices**

The distribution of respondents’ perceived importance of being given choices regarding cognitive testing for each domain is provided in Table 4. Higher values for the 5-point Likert ratings represented higher levels of agreement with importance. Generally, importance ratings were high for all domains, with a median of 4, and a range of 1–5.

Nonparametric Mann-Whitney tests indicated that those who endorsed preferences in a given test domain also gave higher importance ratings in that domain compared to those who did not have preferences. The median importance ratings of those with preferences were 1–2 points higher than those with no preferences in all domains of cognitive testing (modality [$p = 0.00$]; location [$p = 0.00$]; company [$p = 0.00$]; negative result delivery [$p = 0.00$]; positive result delivery [$p = 0.00$]). Female gender was associated with higher importance ratings. Specifically, women gave higher ratings for choosing the location ($p = 0.03$), company ($p = 0.00$), and result delivery ($p = 0.00$) than men.

**Willingness**

The majority of respondents were willing to engage in cognitive testing (85.5%), with a small proportion reporting they were ambivalent (10.5%) or in disagreement to testing (4.0%). None of the person variables was associated with willingness.

Results of binary logistic regressions predicting willingness to engage in cognitive testing are summarized in Table 5. The variable that predicted willingness to engage in cognitive testing was importance of choosing location. Lower perceived importance of choosing the location of the cognitive test predicts willingness to engage in cognitive testing ($p = 0.04$).

**Discussion**

Sparse literature exists on older adults’ attitudes towards cognitive tests [11, 32]. The present study is the first to elicit older adults’ specific preferences in five domains of the cognitive test experience, the value they place in being given choices in those five domains, and their willingness to undergo cognitive testing. Overall, we found support for our hypotheses that older adults have preferences regarding the test-taking experience and they
attach substantial importance to these preferences. Women and those with subjective cognitive concerns were more likely to endorse preferences in multiple domains. Somewhat surprisingly, most participants were willing to take part in cognitive testing, and their willingness was generally not associated with having preferences and valuing choices.

About half of respondents had preferences for modality and location, whereas a large majority endorsed preferences regarding company. Respondents also gave high importance ratings for having choices in these domains of cognitive testing. A frequently endorsed combination of preferences was to take the cognitive test on a computer or mobile device, at home, and alone. This preference pattern provides support for the use of telehealth to administer cognitive tests. Telehealth is a system of technology that allows for the remote provision of medical services using videoconferencing technologies and provides an alternative medium for cognitive assessment. Telehealth is thus a means that could potentially satisfy the most popular endorsed preferences in this study, allowing older adults to take diagnostically informative tests at home, by themselves, and with a computer or mobile device. While the reliability and validity of cognitive assessments via telehealth remains to be fully established, this

Table 5. Summary of binary logistic regression model results to predict willingness to engage in cognitive testing

| Variable                        | Odds ratio | SE  | p     | 95% CI lower bound | 95% CI upper bound |
|---------------------------------|------------|-----|-------|--------------------|--------------------|
| Modality Gender                 | 1.31       | 0.36| 0.46  | 0.65               | 2.64               |
| Subjective cognitive concern    | 1.37       | 0.35| 0.37  | 0.69               | 2.74               |
| Preference                      | 0.87       | 0.35| 0.70  | 0.44               | 1.73               |
| Gender                          | 1.49       | 0.36| 0.26  | 0.74               | 2.99               |
| Subjective cognitive concern    | 1.35       | 0.35| 0.40  | 0.68               | 2.68               |
| Importance                      | 0.86       | 0.15| 0.32  | 0.64               | 1.16               |
| Location Gender                 | 1.25       | 0.37| 0.55  | 0.61               | 2.54               |
| Subjective cognitive concern    | 1.41       | 0.35| 0.33  | 0.70               | 2.81               |
| Preference                      | 0.76       | 0.35| 0.43  | 0.38               | 1.51               |
| Gender                          | 1.56       | 0.36| 0.21  | 0.78               | 3.16               |
| Subjective cognitive concern    | 1.31       | 0.35| 0.44  | 0.66               | 2.61               |
| Importance                      | 0.72       | 0.16| 0.04* | 0.52               | 0.99               |
| Company Gender                  | 1.13       | 0.36| 0.74  | 0.55               | 2.29               |
| Subjective cognitive concern    | 1.25       | 0.35| 0.53  | 0.63               | 2.48               |
| Preference                      | 1.46       | 0.40| 0.35  | 0.66               | 3.21               |
| Gender                          | 1.38       | 0.35| 0.36  | 0.69               | 2.77               |
| Subjective cognitive concern    | 1.25       | 0.34| 0.52  | 0.64               | 2.45               |
| Importance                      | 0.92       | 0.15| 0.07  | 0.69               | 1.23               |
| Result delivery Gender          | 1.27       | 0.38| 0.53  | 0.61               | 2.66               |
| Subjective cognitive concern    | 1.25       | 0.37| 0.56  | 0.60               | 2.58               |
| Preference (negative results)   | 1.65       | 0.41| 0.22  | 0.74               | 3.67               |
| Gender                          | 1.48       | 0.38| 0.30  | 0.71               | 3.08               |
| Subjective cognitive concern    | 1.33       | 0.37| 0.44  | 0.64               | 2.76               |
| Preference (positive results)   | 2.14       | 0.50| 0.13  | 0.81               | 5.66               |
| Gender                          | 1.20       | 0.36| 0.61  | 0.60               | 2.41               |
| Subjective cognitive concern    | 1.23       | 0.35| 0.55  | 0.62               | 2.43               |
| Importance                      | 1.33       | 0.17| 0.09  | 0.96               | 1.84               |
approach promises utility in the assessment of cognitive functioning among older adults in rural, underserved areas [33, 34].

The most sensitive domain was delivery of results, where a large majority of respondents had specific preferences and placed unequivocal value on having choices in the matter. Preferences were contingent on the type of results, with most people preferring to receive negative results through a telephone call and positive results through an office visit. The high value placed on preferences and choices with regard to test results suggest that it may be of particular importance for healthcare professionals to educate patients about cognitive tests and prepare them for the results they produce, before undertaking testing. At that time, the provider should also explore patients’ preferences regarding the communication of results. Our finding is consistent with other findings suggesting that accommodating patient preferences for the delivery of test results may improve patient-physician communication [35]. It is likely that the responses we obtained in the test result domain may have captured broader concerns regarding the disclosure of results not assessed in the AACT items. These aspects may encompass patients’ need to understand the implications of the results, how results might impact their lives, what decisions need to be made next, and how to share information with family members. Our findings also indicate that the respondents who are the most concerned about the delivery of nonnormal results were those with subjective cognitive concerns. It has been previously reported that only a minority of those with subjective memory complaints seek help for medical concerns [36, 37], even though this group is at an increased risk of developing cognitive impairment or dementia [38]. It may be that the fear of receiving positive results contributes to the apprehension those with subjective cognitive concerns experience in seeking medical help. Probing for subjective concerns and addressing the fear of positive results may also need to be part of the communication that prepares patients for cognitive testing.

An intriguing association emerged between gender, likelihood of having preferences, and the value placed on having choices. Women were more likely to endorse preferences for how they receive negative and positive results of cognitive testing and reported it more important to be given choices around the location, company, and mode of result delivery. These associations suggest women may be more invested in the experience of taking diagnostically informative cognitive tests, further contributing to the literature on the gender disparities seen in engagement with healthcare services. Literature spanning several decades point to men being less likely to use physician services and preventive healthcare measures than women [39], possibly due to men delaying help seeking in the context of their health [39, 40]. The gender differences reported in the current study suggest women may be especially responsive to a person-centered approach to cognitive testing. It remains unknown if proactively involving men in the decision making process would be likely to increase their engagement with utilization of preventive care services, including cognitive screening for the detection of cognitive impairment and dementia. Further investigation into gender and its relations to person-centered care and consequential healthcare utilization is warranted.

While a recent study found that high behavioral intention to undergo screening is positively related to participation in screening for cognitive impairment [41], it is important to note AACT’S measurement of willingness focused on perceived willingness rather than actual testing acceptance behaviors. We expected older adults to exhibit variability in terms of their willingness to engage in cognitive testing. In our sample, the majority of our respondents (85.5%) were willing to engage in cognitive testing. This percentage is much higher than previous estimates of acceptance of cognitive screening or assessment (49 and 52.3%) [12, 30]. The atypically high endorsement of willingness in our sample may explain why we did not find a robust pattern of associations between this variable, endorsed preferences, and importance ratings. The association we found between lower perceived importance of
choosing the location of the cognitive test and higher willingness to engage in cognitive tests is difficult to interpret in isolation. Data from samples drawn from actual health settings may clarify the relationship between patients’ attitudes and behaviors, and ultimately establish the benefits of centering testing around patients’ preferences. Such data could include intervention studies that allowed opportunities for older adults to make choices around the cognitive test experience, and then examining the association between opportunity of choice and willingness to engage in future testing.

There are other limitations to consider in interpreting our findings. First, participants were online survey respondents who self-selected to participate in our study and may represent an opportunistic sample. Further, our respondents were generally younger than 65 years old, and thus our sample may not be representative of the older adults in the primary care population. Accordingly, our results should be confirmed in samples of older adults attending primary care settings. Research concerning data collection using Mechanical Turk indicate that data obtained through this online platform are at least as reliable as those obtained via traditional methods, and that the platform serves as effective and valid tool for behavioral research [42]. However, we recognize that the pattern of endorsed preferences, particularly preferences supporting a telehealth approach, may be specific to MTurk workers. An additional limitation includes AACT’s focus on five pragmatic domains of the test-taking experience. With this emphasis on the concrete circumstances of testing, we may have missed dimensions of the experience that matter to older adults. The AACT questionnaire was developed for this study with largely exploratory aims, and its psychometric properties have not been established. The constructs of attitudes and specific preferences for cognitive tests have not been measured in previous research. Thus, our primary aim was to provide novel information, not to develop a standardized measure. Finally, we did not ask our respondents about their attitudes and preferences for specific types of cognitive testing currently in use (i.e., screening, neuropsychological testing). This distinction is likely important for formulating person-centered approaches and should be investigated in future studies.

In summary, our study provides the first evidence of its kind that opportunities exist for developing a person-centered approach for cognitive testing among older adults. Such opportunities include asking older adults their preferences for the parameters in which they take diagnostically informative tests. It appears that older adults value choices in regard to the testing situation and have variability in preferences for the manner in which they wish to take cognitive tests. A suggested earlier, it remains to be proven that offering choices in the context of cognitive testing, including the use of telehealth and thorough discussions around discussions of results, would lead to better outcomes around cognitive assessment.

Statement of Ethics

All respondents provided informed consent prior to the study. The study protocol was approved by the Pacific University Institutional Review Board.

Disclosure Statement

The authors declare no conflicts of interest in relation to this study. Both authors have read the paper and have agreed to be listed as authors.
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