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COMMENTARY

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Virtual disclosure of preclinical Alzheimer's biomarkers: Preliminary experiences

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INTRODUCTION

Alzheimer's disease (AD) is characterized by the abnormal accumulation of β-amyloid (Aβ) and tau proteins in the brain.[1] Using technological advancements in positron emission tomography (PET) and cerebrospinal fluid assessment, researchers can detect Aβ accumulation a decade or more before cognitive decline. This presents a presymptomatic window in which people at risk for developing AD dementia may be detected.[1] Future pharmacological and non-pharmacological interventions target the preclinical stage of AD to prevent or delay dementia onset.

Sharing AD risk with individuals can result in healthy lifestyle changes and/or long-term planning. Previous studies on disclosure of *APOE* genotype, a genetic risk factor for late-onset AD, demonstrate individuals who learn they are at an increased risk for developing AD are more likely to acquire long-term care insurance[2] and report AD-specific health behavior changes.[3] Researchers have begun studies disclosing AD biomarker information,[4,5] specifically Aβ PET results, to cognitively unimpaired adults. Initial findings suggest individuals who learn they have a positive AD biomarker result are more likely to think about[6] or actually make lifestyle changes.[7] To date, preclinical disclosure of Aβ PET results has been safe and effective at educating individuals about the meaning of their results.[5,8] Additional research is needed, however, to more fully characterize the individual psychosocial impact of learning this information and establishing best practices.[9]

We recently began disclosing Aβ PET results in a research setting to assess the impact of disclosure on psychological well-being, health behaviors, and long-term planning. Our study population comprises cognitively unimpaired older adults enrolled in the Wisconsin Registry for Alzheimer's Prevention.[10] With the onset of the COVID-19 pandemic, much in-person human research halted or transitioned to a virtual format to reduce exposure risk. Given the pandemic state and prior findings that sharing *APOE* genotype via telephone can be conducted safely,[11] we converted our disclosure protocol from face-to-face to virtual visits conducted over televideo. We present here preliminary feasibility findings

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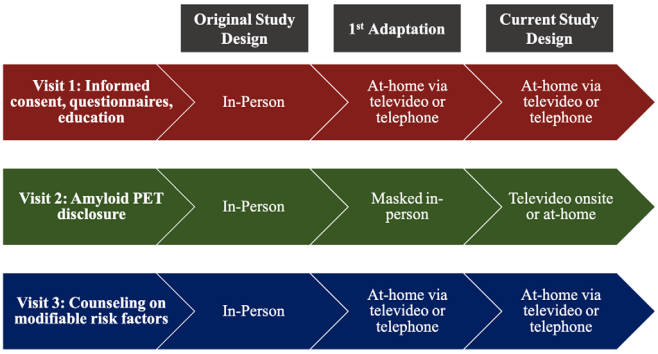

FIGURE 1 Study flow with virtual adaptations. Figure depicts each of the study visits and adaptations to study modality

and initial lessons learned in preclinical Aβ PET disclosure using televideo.

PRELIMINARY FINDINGS: IS Aβ PET DISCLOSURE VIA TELEVIDEO FEASIBLE?

Our study design originally included three in-person visits comprising an education session, disclosure of Aβ PET scan results, and counseling session on reducing modifiable risk factors for dementia (Figure 1). With COVID-19 changing the landscape of clinical care and research, our group discussed the risks and benefits of conducting in-person masked visits as compared to virtual unmasked visits.

While the in-person masked visits facilitated easier interpretation of body language, they presented a risk of viral transmission and hindered facial expression. Further, while visits were in-person they did not feel as intimate as visits prior to COVID-19 due to physical distance between the participant and clinician and inability to provide physical comfort during disclosure. The virtual unmasked visits allowed participants and clinicians to see each other's faces but reduced body language cues and required more competence and familiarity with technology by staff and participants.

To continue the accessibility of our study for participants without necessary technology (e.g., internet bandwidth or device), we adapted the visits to all occur virtually either from home or at the research center (Figure 1). In the at-home televideo visit, the clinician and participant complete a virtual visit using a platform that is compliant with the Health Insurance Portability & Accountability Act (HIPAA-compliant platform). The modified in-person visit looks nearly identical to virtual at-home visits. The clinician and participant complete a virtual visit over research computers and campus internet from separate rooms within the research center. We believe the adaptations to onsite "in-person" visits mitigate virus transmission, are more consistent with the at-home virtual option, and address technological challenges.

To center participant preference, participants can choose modified in-person or at-home virtual disclosure. Currently, as many participants are choosing the at-home virtual visit as in-person (Table 1). Twenty participants have gone through the disclosure visit, 10 at-home and 10 onsite. Three participants were not disclosed to following clinician assessment during the onsite disclosure visit (see the following text). Of those electing at-home disclosure, reasons include ease of access, particularly time and stress saved in not driving to the research center. Additionally, participants have shared being in their homes instead of the research center provides them comfort and a sense of safety when learning their Aβ PET results.

On the whole, technology has worked with minimal issues. We identify people with technological issues at the first study visit to assess feasibility of conducting the disclosure visit at home. Technological issues include not having access to a device or difficulty connecting to the televideo platform. So far, one participant opted for and was unable to complete the disclosure visit at home because of difficulty connecting to the televideo platform. Even though technology worked without issue for this participant at the first visit, their disclosure visit was rescheduled onsite at the research center. Despite some frustration in rescheduling, the onsite disclosure went well.

KEY TAKEAWAYS IN CONDUCTING TELEVIDEO Aβ PET DISCLOSURE

Our primary objectives to develop a safe and effective disclosure process and study postdisclosure outcomes remain consistent despite the COVID-19 pandemic. We have not yet identified any clinically significant changes in symptoms of depression, anxiety, suicidality, or distress following disclosure. In conducting Aβ PET disclosure via televideo, we have learned a considerable amount about disclosure processes.

First, remote visits can be made more personal through intentional emotive facial expressions and gestures. While engagement via a computer presents challenges in expressing the full range of nonverbal communication, clinicians can cultivate a more personal experience for participants by using hand gestures and facial expressions to convey support and understanding. Participants have reported "feeling heard" during the postdisclosure conversation as well as commented on the "empathetic care" of the clinicians.

TABLE 1 Study visit completion

	Visit 1: Education and informed consent	Visit 2: Disclosure of Aβ results	Visit 3: Lifestyle counseling
Participants enrolled[a] (*n*)	21	20 ($n = 3$ not disclosed to)	17
Completed in-person (*n*)	0	10 ($n = 3$ not disclosed to)	0
Completed at home virtually (*n*)	21	10	17
Experienced technological issues requiring study modality adaptation[b] (*n*)	3	1	4

Note: The table reflects data collected as of March 19, 2021. Data collection is ongoing.

[a]Number of people who have completed the visit.

[b]For Visit 2, study modality adaptation refers to converting from an at-home televideo visit to onsite televideo visit. For Visit 1 and 3, study modality adaptation refers to converting from televideo to telephone.

Second, our experience demonstrates the feasibility of healthcare professionals delivering sensitive health-related information in-person and remotely. Nurse practitioners and physicians have effectively conducted disclosure such that participant safety and understanding of results are prioritized. Our clinical study team of nurse practitioners and a geriatrician was trained on the role of Aβ in AD and research. They role-played potential disclosure visit scenarios to practice. The clinicians developed a frequently asked questions document to ensure standardization and completeness of responses. In preliminary assessment of competency in Aβ disclosure, the clinicians have exceeded pre-established study metrics for visit effectiveness.

Third, full team meetings are imperative. Including clinical and nonclinical research members in debriefs regarding cases and overall progress has been essential for study cohesion and understanding. For the clinicians, learning the scientific rationale behind each visit component provides important context. Understanding the scientific rationale can inform the clinicians to approach visits from both a clinical and research perspective, improving participant experience and ensuring adequate data collection. For the nonclinical team members, understanding the critical "on-the-ground" components to actualizing study visits provides valuable insight into the impact of biomedical research on individuals.

Last, the clinical judgment of the study clinician is fundamental in fully determining participant preparedness to learn their Aβ PET result. Despite passing psychological screeners and reporting readiness to learn their results to study coordinators, select research participants were identified as "high risk" for disclosure during the predisclosure clinician interview. In this section of the visit, the clinician asks a set of open-ended questions and assesses the participant's responses for readiness to learn results and potential negative psychological impact following disclosure. The predisclosure clinician interview provides a nonjudgmental space for participants to share their experience with Alzheimer's disease and thoughts about how learning their Aβ PET results may impact their lives. This structured interview has been invaluable in identifying risk for negative consequences the validated questionnaires for depression, anxiety, and suicidality symptoms are not sensitive enough to detect. To date, three individuals passed screening questionnaires and were ultimately not disclosed to following the clinician interview. After an explanation was provided, the participants thanked the study team for not disclosing their Aβ PET results, expressed relief, and continue to support the efforts of the research program.

CONCLUSION

Our preliminary experience suggests Aβ PET disclosure can be conducted safely and effectively via televideo for cognitively unimpaired older adults already enrolled in Alzheimer's research. As data collection continues, we will further assess the safety, efficacy, and feasibility of virtual Aβ PET disclosure. While we adapted our study to a virtual setting out of necessity, our findings suggest a new avenue for disclosure research. Virtual disclosure can increase the accessibility of such studies, reduce participant burden for travel, and can even increase a participant's comfort as they are able to learn potentially sensitive results from the comfort of their homes. Proliferation of computers or other devices, high-speed internet, and technological awareness are barriers to virtual disclosure. Although telemedicine may increase access to healthcare or research studies, virtual visits may further health disparities as technology is cost-prohibitive and may not be available to all communities, such as in rural areas. As such, virtual disclosure may not be ideal or possible for everyone. However, it is a feasible and, in some cases, preferable modality to receive information. Understanding the process of AD biomarker disclosure, especially virtually, will be important for informing protocols

in clinical settings as disclosure encompasses the sharing of biomarkers, genetic information, cognitive testing results, and diagnoses. As we continue to gather data on feasibility and disclosure outcomes, we hope our study results can guide potential disclosure best practices, especially in a virtual setting.

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CONFLICT OF INTEREST

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AUTHOR CONTRIBUTIONS

All authors contributed to the article concept and recommendations. All authors contributed to the manuscript preparation.

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