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RESEARCH ARTICLE

Developing the Healthy Actions and Lifestyles to Avoid Dementia or *Hispanos y el ALTo a la Demencia* program

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Abstract

INTRODUCTION: With Alzheimer's disease and related dementias (ADRD) representing an enormous public health challenge, there is a need to support individuals in learning about and addressing their modifiable risk factors (e.g., diet, sleep, and physical activity) to prevent or delay dementia onset. However, there is limited availability for evidence-informed tools that deliver both quality education and support for positive behavior change such as by increasing self-efficacy and personalizing goal setting. Tools that address the needs of Latino/a, at higher risk for ADRD, are even more scarce.

METHODS: We established a multidisciplinary team to develop the Healthy Actions and Lifestyles to Avoid Dementia *or Hispanos y el ALTo a la Demencia* (HALT-AD) program, a bilingual online personalized platform to educate and motivate participants to modify their risk factors for dementia. Grounded in social cognitive theory and following a cultural adaptation framework with guidance from a community advisory board, we developed HALT-AD iteratively through several cycles of rapid prototype development, user-centered evaluation through pilot testing and community feedback, and refinement.

RESULTS: Using this iterative approach allowed for more than 100 improvements in the content, features, and design of HALT-AD to improve the program's usability and alignment with the interests and educational/behavior change support needs of its target audience. Illustrative examples of how pilot data and community feedback informed improvements are provided.

DISCUSSION: Developing HALT-AD iteratively required learning through trial and error and flexibility in workflows, contrary to traditional program development methods that rely on rigid, pre-set requirements. In addition to efficacy trials, studies are needed to identify mechanisms for effective behavior change, which might be culturally specific. Flexible and personalized educational offerings are likely to be important in modifying risk trajectories in ADRD.

KEYWORDS
behavior change, dementia, digital learning, education, health equity, LatinX, modifiable risk factors, online program, risk reduction, social cognitive theory

1 | INTRODUCTION

Alzheimer's disease and related dementias (ADRD) represent an enormous public health challenge, with the total number of persons with dementia continuing to rise worldwide. In the United States alone, more than one in nine adults 65 years of age or older are affected by AD.[1] Not only does ADRD have a devastating impact on afflicted individuals and their families, it is also hugely expensive. The lifetime cost per patient is estimated at $341,000, which translates to an estimated annual cost of $1 trillion in the United States by 2050.[1] Although there is yet to be a cure for ADRD, delaying symptom onset by 5 years may lead to 2.7 additional life-years and care cost savings of ≈$500,000 per person.[2,3] With the high economic, medical, individual, and societal burden of ADRD, there is an urgent need to prevent or delay dementia onset.

Chronic conditions including hypertension and sleep apnea, as well as lifestyle factors including social isolation and physical inactivity, have been linked to increased dementia risk. It is important to note that these conditions and lifestyle factors can potentially be improved through successful interventions.[4–7] Targeting these and other modifiable risk factors (MRFs) provides an opportunity to reduce dementia risk. Indeed, The Lancet Commission reported that across the lifespan, up to 40% of the population attributable risk is related to MRFs.[8] The timeliness and importance of targeting MRFs are also reflected in The National Plan to Address Alzheimer's Disease,[9] which endorses the goal to promote healthy aging and reduce dementia MRFs.

Most mid-life and older adults are unaware of their own MRFs and/or the potential to reduce their dementia risk via lifestyle modification.[10,11] Many also do not have the motivation, know-how, or psychosocial support systems needed to modify their lifestyles successfully and sustainably.[12,13] Collectively, these findings underscore a critical translational gap that exists between what is reported in the scientific literature and what is communicated and made available to the public to educate, motivate, and support behavior change to prevent dementia.

According to social cognitive theory (SCT), behavior is a function of the interaction between individuals, their environment, and the behaviors themselves.[14] Key factors that influence this dynamic relationship include self-efficacy, goals, and outcome expectations. Therefore, to promote behavior change it is important to address all of these components. For example, individuals are more likely to continue exercising if they not only learn about the importance of exercise to maintain cognitive health, but also set small goals to gradually increase confidence in their ability to exercise and feel rewarded by experiencing benefits. For dementia risk reduction, interventions that address outcome expectations and increase knowledge regarding dementia MRFs are key components to support behavior change. Educational interventions have been shown to improve knowledge and belief in the importance of health behaviors for dementia among healthy adults, adults at-risk of dementia, and among dementia patient caregivers.[15–17] However, there is limited availability for evidence-informed tool(s) that deliver quality education about dementia risk reduction and that incorporate other aspects such as increasing self-efficacy and goal setting to support positive behavior change.[18–22] These tools would be particularly helpful in primary care and geriatric health clinics where fast-paced health care delivery and limited resources often limit effective education and support for behavioral modification.[23] Equally important would be offering these tools to the public to complement awareness campaigns and further galvanize the public's interest in and commitment toward dementia prevention.

Recognizing the significance of reducing dementia MRFs in the United States as well as the timely need for effective educational tools that can be scalable and malleable to support use in varied settings, we have developed the online program in English and Spanish: Healthy Actions and Lifestyles to Avoid Dementia (HALT-AD) *or Hispanos y el ALTo a la Demencia*. The HALT-AD program is an online personalized platform to educate and motivate participants to modify their risk factors for dementia. The online format was selected given the recent advancements in accessible and cost-efficient digital learning technologies; the increased access to telehealth, especially during the coronavirus disease 2019 (COVID-19) pandemic, and rising computer literacy among mid-life and older adults.[24] To promote health equity, we developed a version of HALT-AD tailored specifically to Latino/a, since this group has a 1.5 times higher risk of developing ADRD compared to non-Latino Americans,[1] and MRF interventions to reduce dementia risk are only beginning to emerge in this growing segment of the U.S. population. Furthermore, our local population in San Diego is composed of at least 35% Latino/a.[25] With two versions of the program (English and Spanish), the program would likely be accessible to a large proportion of older adults in the United States.

The aims of the current article are to describe the iterative development of the HALT-AD program and the rationale behind its use. We provide specific examples of how applying the methods used helped inform program development, along with a discussion on challenges and future considerations.

2 | METHODS

2.1 | Summary of the HALT-AD program

HALT-AD is a personalized, interactive, and bilingual (English and Spanish) online platform that helps mid-life and older adults learn about and

identify their own dementia MRFs and how these may be addressed by behavioral change in lifestyle (Figure 1). Through a self-directed and remote learning approach, HALT-AD can be accessed using internet on a computer, tablet, or smart phone, at convenient times, and at the user's own pace.

After signing up and completing baseline questionnaires, participants receive personalized lifestyle risk profiles, set their own health and behavior change goals, and access the educational program that can be personalized (**platform screenshots in** File S1). Through topic-specific modules, participants learn about their risk factors and how to effectively modify them (Figure 2). Because appropriate goal setting helps with setting expectations for behavior change outcomes and is an important determinant of effective behavior change,[26,27] the introductory module covers the concept and importance of setting SMART goals (Specific, Measurable, Attainable, Realistic, and Time-Bound), along with examples on how to set personal SMART goals for lifestyle modification. The SMART goal concept is then re-introduced in the remaining modules, providing additional examples that are specific to the MRF-of-focus in each module. In addition to learning through modules, participants set behavior change goals and track progress toward goal attainment and improved knowledge within the platform itself. HALT-AD further incentivizes participation via motivational reminders (phone and email messages) and provision of reward badges. At the end of the program, participants redeem badges for their certificate of completion.

Each module includes easy-to-digest educational content in the form of text, pictures, and cartoons, as well as interactive features such as learning activities (e.g., matching games, case studies, flip cards, review questions), expert videos, audio summaries, and optional lessons for a higher-level scientific dive. Examples of the latter include video interviews with specialized clinicians and researchers discussing in lay terms peer-reviewed ADRD publications and their relevance/applications in the "real-world."

From a technical standpoint, HALT-AD was developed on the University California San Diego Amazon Web Services (AWS) cloud infrastructure. The front end was crafted with Angular 12 and the back end with Java Spring Boot.

Recognizing the critical nature of data privacy, HALT-AD was designed in adherence to Health Insurance Portability and Accountability Act (HIPAA) guidelines.

RESEARCH IN CONTEXT

1. **Systematic review**: After reviewing the peer-reviewed literature via PubMed, the authors identified a limited number of studies focused on the development of online educational programs that support behavior change for reduction in modifiable risk factors in Alzheimer's disease and related dementias (ADRD) among Latino/a. The methodological approach to develop and test such programs is less described. Identified programs have been cited appropriately.
2. **Interpretation**: The description of our methodological approach to develop the Healthy Actions and Lifestyles to Avoid Dementia *or Hispanos y el ALTo a la Demencia* (HALT-AD) program helps advance knowledge on the requirements, process, potential workflows, advantages, and challenges to using iterative pilot testing and community engagement to build a program with and for the Latino/a community.
3. **Future directions**: The authors propose the use of the National Institutes of Health (NIH) Stage Model for Behavioral Intervention Development to test the efficacy and real-world effectiveness of HALT-AD among Latino/a and other understudied groups in the United States.

2.2 | The method for HALT-AD program development

2.2.1 | Overview of requirements and method

Creating HALT-AD involved developing three main components concurrently and iteratively: (1) a web-based platform that is "fit for use" and also meets regulatory HIPAA requirements and Web Content Accessibility Guidelines (WCAG) standards; (2) educational content that is understandable and engaging to a 50-85-year-old, English-speaking general audience and Latino/a in the United States; and (3) content designed for personalized behavioral change that is poised to effectively educate and support lifestyle modification.

To develop these three components, we established an interdisciplinary team of more than 40 professionals in neurology, neuropsychology, behavioral research, digital learning, user experience design, health information technology (IT), and software engineering (Table S1). We developed a community advisory board (CAB) with members fluent in English and/or Spanish, consisting of volunteers committed to supporting dementia prevention research and/or promoting health equity. CAB members had personal experiences with dementia as caregivers or patient relatives or had career backgrounds related to community outreach and education. Specialized smaller working groups completed activities that spanned 2 years for the development of HALT-AD (Figure 3).

2.2.2 | Key characteristics of the method and justification

(1) Iterative user-centered design combined with agile software development: The traditional approach to developing a program like HALT-AD has been the "waterfall" approach, wherein the program is developed in one-go using sequential phases with pre-set unmodifiable requirements.[28] In digital learning programs, for example,

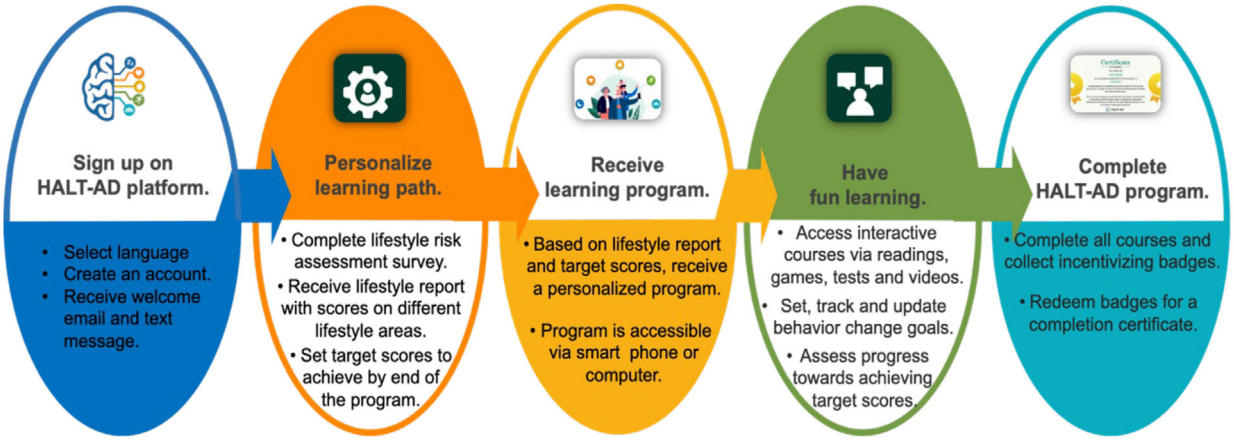

FIGURE 1 Sequential components of the HALT-AD program. HALT-AD, Healthy Actions and Lifestyles to Avoid Dementia *or Hispanos y el ALTo a la Demencia* program.

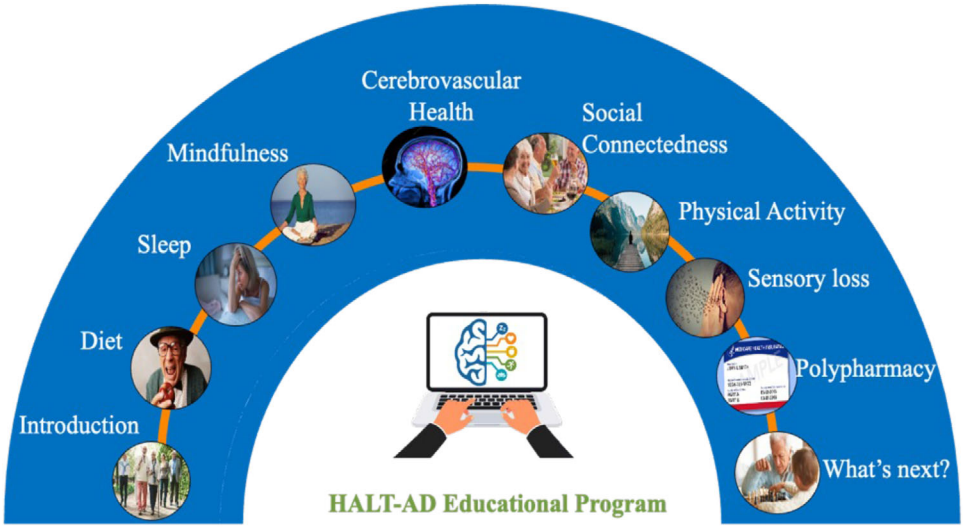

FIGURE 2 List of topic-specific modules offered in the HALT-AD program. HALT-AD, Healthy Actions and Lifestyles to Avoid Dementia *or Hispanos y el ALTo a la Demencia* program.

requirements might include pre-defining the types of interactive features to be included and the number and length of modules. Using this approach often described as inefficient and rigid,[29–32] there is little to no room for rapid improvements based on user experience with the program itself before it is finalized. In practice, although finalization can mean the program is considered ready for dissemination and use in the "real-world," in research it likely means it is ready for efficacy, effectiveness, and implementation trials. Without improvements before program finalization, risk is high for costly and time-consuming trials that do not show meaningful impact on educational, behavioral, or health outcomes. Having to "go back to the drawing board" and to establish operational teams that revise the program after failed trials is an additional roadblocks against timely access to an effective program by community members or patients that need it the most.

Instead, the HALT-AD program components underwent several cycles of rapid development, user-centered evaluation, and refining by the same operational team (Figure 3). For example, the educational content was reviewed and revised multiple times following feedback from CAB via semi-structured Qualtrics surveys and phone/email conversations (Figure 3A). Feedback focused on specific improvements to module design (e.g., usability of interactive features, sensory appeal) as well as content (e.g., length, clarity, usefulness, relevance, cultural appropriateness). In addition, iterations were informed by data generated relatively quickly from two small studies and a survey of study participants (Figure 3C–F); Table S2). In Table S2, a description for each study's aims and methods is provided for additional context. In summary, by leveraging frequent feedback and trial and error, our iterative, user-centered design approach[30] combined with Agile

FIGURE 3 Summary of a community-engaged, data-driven, and iterative method for HALT-AD program development. (A) Educational content developed by researchers, clinicians, science communicator, and a community advisory board (CAB). (B) Information technology programming, content incorporation, and design to develop platform prototype.(C–F) Two rounds of prototype pilot testing studies and data analysis, followed by development of a refined data-informed version of the platform. (G) Collecting and analyzing survey data on facilitators and barriers for community members' participation to also inform program implementation strategies.

software development[33] allowed making improvements to the program efficiently as it was being developed.

(2) Community-based participatory design: Community members, serving as volunteer advisors or study participants, provided input to help develop the educational content and platform features of HALT-AD, to identify effective approaches for participant recruitment and efficient data collection, and finally to refine our research questions based on community feedback. Not only were community members used in the evaluations of designs (a user-centered design approach), but they also participated in the design process by offering key design insights and objectives for the overall experience (Table S2). This followed recommendations for participatory design and research, as well as co-creation and co-design.[34–36]

(3) **Culturally adapted program**: Cultural adaptation was undertaken to ensure that the Spanish version of HALT-AD was culturally sensitive and likely to meet the needs and match the values of our target population, enhancing effectiveness and leading to better adherence.[37] This Spanish version was culturally adapted for Latino/a by employing a planned, organized, iterative, and collaborative process with both CAB and study participants as members of the Latino/a community.[36] We followed a framework of information gathering (e.g., interests and needs from CAB via surveys and Latino/a staff via meetings), preliminary adaptation (e.g., developing parts of HALT-AD based on gathered information), adaptation tests (e.g., pilot testing usability with study participants), and, finally, adaptation refinement (e.g., modifying HALT-AD based on pilot results).[38,39] We incorporated content and design features that align with the traditions, customs, general interests, and other aspects of Latino/a cultural identities as well as ensured that translations did not lose meaning. For example, based on CAB and participant feedback, the Spanish version of the platform is much more colorful (more reds, yellows, and greens), has more pictures of Latino/a (focus on family, food, dance, and music), and has less text within the modules compared to the English version. In addition, based on Latino/a feedback, we revised both versions of the platform

to include short educational videos (i.e., <5 min each, interviews with experts discussing science in lay terms). Rather than using software to automatically generate subtitles in Spanish, the subtitles were also translated by our team to ensure approachability with a wide Latino/a audience. Recognizing the rich cultural diversity and heterogeneity among Latino/a, our team included Latino/a researchers, staff, CAB members and participants from different countries and backgrounds (i.e., Chile, Mexico, Venezuela, Peru, and the United States). The occasions when team members' opinions differed substantially about the most appropriate translation of a specific term or terms were infrequent. When disagreements did arise, there was an open dialogue and discussion by Zoom and/or email to identify a translation that would likely be understood by most Latinos/as.

3 | RESULTS

In Table 1, we provide sample examples illustrating the iterative development of HALT-AD, as informed by study findings. There has been more than 100 findings and action items taken to date. Selected examples are illustrative and intended to be understood by a broad audience with varying levels of technical expertise.

4 | DISCUSSION

In this article we describe our iterative methodological approach that guided the development of HALT-AD, an online program aimed at educating and supporting lifestyle changes to reduce MRFs for dementia. During its 2-year development process, we were guided by feedback from the community and data from three small studies to iteratively revise two prototypes that led to the HALT-AD program in its current form. HALT-AD's educational content (breadth, depth, and tone), esthetics, and interactive features have evolved greatly from its first prototype, even though the first prototype was developed using best digital industry practices and following principles of SCT. Some of the critical factors in this development have been the incorporation of and research partnership with community advisors and staff from the intended community users. Through the additional investment of some months upfront, HALT-AD was able to evolve into a program that has a "look and feel" closer to the educational and behavior change needs of many of the community members it will likely serve, especially Latino/a. Although the scope of this article covers the description of HALT-AD development, it would be valuable for us and others to conduct a comparative study specifically within the ADRD prevention field whereby different methodological approaches are applied in tandem (e.g., iterative vs not; community-engaged vs not), after which management and program outcome metrics are compared.

In reflecting on our experience developing HALT-AD, we identified several strengths that made applying this method possible. Consistent with the principles of agile methods,[31] keeping a flexible mindset and accepting experimentation via trial and error allowed the HALT-AD operational team to move quickly but purposefully from data analysis to interpretation and then to experimentation again, with the conviction that the community and study participants will "let us know if that is what they need or how to make it better." This is contrary to traditional methodologies, notably the Waterfall model, which favor a more rigid and linear progression. The Waterfall model emphasizes exhaustive requirements gathering at the outset, followed by a strict sequence of design, implementation, and testing phases. Within this framework, revisiting prior stages based on new insights or feedback is often seen as costly and disruptive. This can discourage experimentation, as deviations from the initial plan might lead to delays and increased costs. The rigidity of such models can sometimes hinder adaptability, making it challenging to incorporate unforeseen changes or address issues that emerge later in the development process.

However, applying this iterative method requires consistent communication and decision-making within and across operational teams with widely different areas of expertise (e.g., between a neurologist and IT programmer around a feasible algorithm that qualitatively determines risk for dementia due to sleep apnea). Navigating communication and decision-making efficiently and effectively is accomplished by having flexible workflows instead of standard operating procedures, designating team members as liaison with the community, and having a project manager with overall responsibility for integrating and coordinating cross-functional activities. Our interdisciplinary team, spanning multiple disciplines (medicine, psychology, human-centered design) and practices (researchers and software developers), provides a notable example that may be interesting for emerging research on team science, particularly as it considers the role of teams operating in the space of digital learning and disease prevention.[40]

Although an educational program developed iteratively with cultural adaptation may be better positioned to be efficacious and effective,[41] there are limitations. Collecting pilot data to improve feasibility, acceptability, or usability of a program does not obviate the need for trials that can test efficacy or real-world effectiveness. Although there has been specific linguistic and cultural development within HALT-AD with input from its CAB and Latino/a participants, it remains to be determined if increased knowledge and positive behavior among Latino/a is achieved. The iterative process solicited extremely valuable qualitative and quantitative feedback via surveys, interviews, and focus groups. However, generalizability is limited by sample size that will be addressed in future studies. Future work will be based on the National Institutes of Health (NIH) stage model for behavior change,[42] allowing the identification of mechanisms of behavior change that work (and those that do not), which would then facilitate an efficient, scalable adaptation of HALT-AD for use in different settings. Finally, and more broadly, digital education programs such as HALT-AD should not be considered a replacement, but rather an alternative option or supplement to traditional educational approaches, since personal learning preferences, various health conditions (e.g., vision, hearing), technical literacy, and internet access may influence usability and benefit from digital programs. For instance, among Americans age 65 years of age and older, ≈75% report using the internet and nearly 42% lack wireline broadband access at home, with higher proportions of African Americans and Latinos being offline compared to Whites.[43,44]

TABLE 1 Sample examples of the iterative and data-informed development of HALT-AD.

Finding	Finding interpreted as need for:	Action taken
From study 1[a]		
a. Related to content delivery: During post-intervention focus group, most participants reported feeling patronized and demotivated by an interactive feature: a virtual doctor either smiling/gesturing with thumbs up or frowning/thumbs down in response to participant's answer on a review question.	More neutral feedback on answers to review questions	Remove interactive feature and instead, provide feedback by writing "correct" or "incorrect" with an option to try again.
b. Related to engagement: Only 10 participants (53%) completed all their modules. Focus group data revealed three barriers: (1) forgetting; (2) feeling program did not help identify how to improve lifestyle given own circumstances; (3) feeling program lacked provision of feedback, especially when progress was being made.	a. Frequent reminders b. More personalization c. More feedback	a. Add automatic welcome email and SMS upon sign-up. b. Send weekly reminders via SMS with motivational messaging and weblink to platform. c. Create content to educate about SMART[b] goal setting d. Add features that allow participants to set and save their own SMART goals, track progress over time and receive pop-up feedback based on progress. e. Add feature that allows participants to collect reward badges, redeemable for a certificate at the end of program.
From study 2[c]		
a. Related to content delivery: No comments during 1:1 interviews on answer response (correct/incorrect) to review questions in contract to Study 1.	No change in style of feedback style to answers on review questions	Keep feedback style in final version of the program.
b. Related to reward badges: 1:1 interview data showed 1 out of the 10 participants did not find the badges valuable to his motivation or need for feedback. Remaining participants mentioned the feature was valuable but looked and sounded childish.	More formal-looking and formal-sounding badges	Re-design and rename badges to look more formal (**Figure S1**).
From study 3[d]		
a. Related to program participation: A higher % Latino/a compared to non-Latino/a (16.1% vs 4.70%) reported access to a smart phone or computer as a barrier to participation.	More equitable access to technology that enables access to HALT-AD	a. Create a tutorial video that provides technological guidance for users with less experience using a computer or smart phone. b. Work in progress: Identify funding avenues to provide pre-paid and data-enabled tablets to users without hardware and/or internet.
b. Related to support for behavior change: Higher % Latino/a compared to non-Latino/a (60.5% vs 40.0%) prefer psychosocial support groups over an only self-directed program. No difference by ethnicity with interest in including wearable devices for tracking behavior.	Personalization of mode of behavior change support	Develop technical processes that will streamline future modifications in psychosocial support features (e.g., notifications for support sessions, messaging to help desk) based on target-user characteristics or preferences.

[a]An interventional trial to evaluate HALT-AD's first prototype, which included four modules and offered monthly, facilitated group discussion sessions.
[b]SMART acronym is for specific, measurable, attainable, realistic, and time bound.
[c]An interventional trial to test the usability of and engagement with the second prototype of HALT-AD, which included six modules and no facilitated group discussions.
[d]A survey study to identify interest, facilitators, and barriers of participation in HALT-AD.

In looking to the future of HALT-AD, the development model we have used can inform the adaptation process of HALT-AD to other underrepresented minority populations and underserved communities, such as developing additional versions of HALT-AD in different languages. Further personalizing behavioral support features such as including wearable devices, coaching, and psychosocial support group sessions, in addition to sustaining and updating the platform as new scientific evidence emerges and finding a fiscal model for HALT-AD's implementation, will all need to be further addressed as data relating to its efficacy and effectiveness are acquired. Finally, by sharing our experience with the ADRD research and practice community, we hope to help accelerate the development and implementation of other data-informed tools that can successfully support individuals in reducing their dementia MRFs.

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CONFLICT OF INTEREST STATEMENT

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CONSENT STATEMENT

All study participants provided signed informed consent.

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SUPPORTING INFORMATION

Additional supporting information can be found online in the Supporting Information section at the end of this article.

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