The Aliviado Caregiving Application: An Iterative, Human-Centered Design Study

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Submitted to: JMIR Formative Research
on: August 22, 2025

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Abstract

Background: Care partners (CPs) of persons living with dementia (PLWD) face complex caregiving responsibilities that are worsened by a lack of access to non-pharmacological interventions and decision support for behavioral and psychological symptoms of dementia.

Objective: This manuscript describes our iterative, human-centered design to tailor our existing evidence-based Aliviado Caregiving mobile health (mHealth) app for diverse informal CPs.

Methods: We utilized a three-stage process to refine and revise the initial Aliviado Caregiving wireframes. Multiple key participants were recruited, including an investigator team and clinician users (n=101) in Stage 1, CPs of PLWD (n=8) in Stage 2, and a community advisory board (n=8) in Stage 3. Descriptive statistics were used to summarize clinician characteristics and identify key features for the initial CP app wireframes in Stage 1. Reflexive thematic analysis was applied to qualitative transcripts in Stages 2 and 3.

Results: Descriptive statistics of the clinician survey found that key features of a CP app included “CP stress management strategies/intervention” (84%) and “CP stress self-monitoring/tracking” (69%). Four qualitative themes were identified: 1) User-Interface Design Preferences and Suggestions, 2) User-Friendly Language, 3) User-Concern Prioritization, and 4) Future Application Features.

Conclusions: Applying co-design principles improved our ability to enhance the acceptability, feasibility, and usability of the Aliviado Caregiving app for future testing in a pilot project.

(JMIR Preprints 22/08/2025:82862)
DOI: https://doi.org/10.2196/preprints.82862

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Title Page

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STATEMENTS AND DECLARATIONS

Paper Type: Original Paper

Conflicts of Interest
The authors have no conflicts of interest to disclose.

Funding
This work was supported by the National Institute on Aging (R33AG061904 and P30AG073105) and the NYU Discovery Research Fund for Human Health. The content is solely the responsibility of the authors and does not necessarily represent the official views of the National Institutes of Health.

Word Count: 3257

Key Words: caregiving; co-design; digital health; mobile app

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Introduction

Care partners (CPs) such as adult children and spouses provide most care to persons living with dementia (PLWD) living in the community. A nationally representative sample found that CPs of PLWD were more engaged in most types of assistance compared with CPs of adults without dementia, including household activities (92% vs 87%), healthcare system interaction (79% vs 61%), health/medical care (76% vs 60%), and self-care or mobility activities (71% vs 60%) [1]. The ability

to carry out these activities is significantly impacted by behavioral and psychological symptoms of dementia (BPSD), such as agitation, depression, or wandering, where CPs are rarely provided effective training or assistance, and healthcare team members likewise lack awareness of evidence-based practices, particularly non-pharmacologic ones [2].

BPSD significantly increase caregiver burden, often leading to stress, burnout, and poor physical and mental health [3]. The bi-directional relationship between BPSD and caregiver well-being means that worsening symptoms in PLWD can intensify caregiver strain, which in turn exacerbates the symptoms of dementia [4]. CPs frequently struggle to determine which BPSD to prioritize, as symptoms vary in severity and impact. For instance, while agitation may pose immediate safety concerns, depressive symptoms could undermine the overall quality of life for both the CP and the care recipient. These challenges are especially pronounced in underserved communities, where CPs often lack access to any resources or support, let alone ones tailored for their specific community, compounding the difficulty of managing BPSD effectively [5].

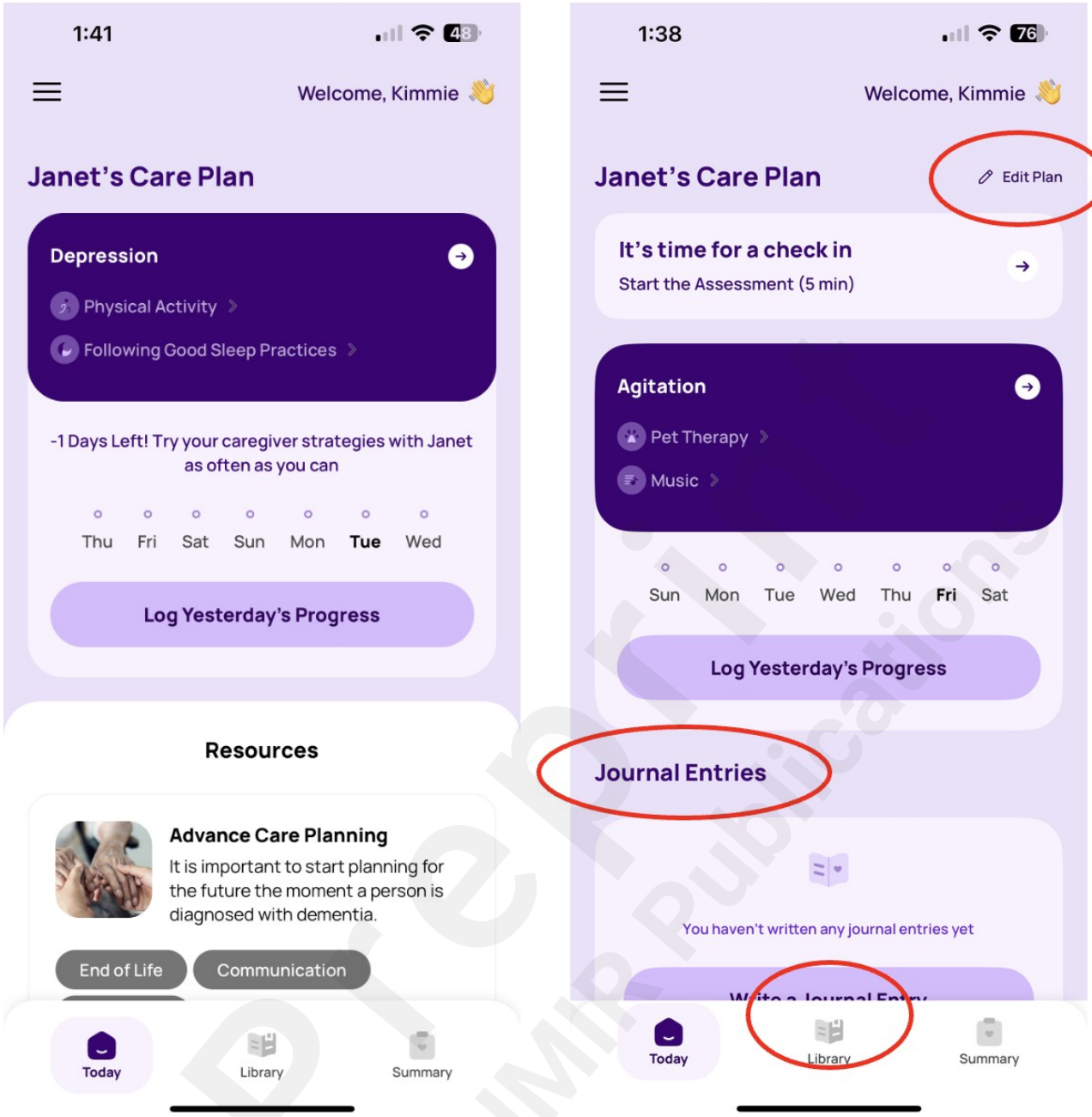
Disparities in supporting CPs are significant, particularly for those from marginalized communities. Racially and ethnically diverse informal CPs often find more meaning in positive aspects of caregiving, which can have a protective effect, yet also often lack access to evidence-based training or high-quality non-pharmacological interventions for BPSD [6,7]. Black and Latino CPs also report higher care needs, less access to paid care services, and greater levels of depression compared to non-Hispanic White CPs [8]. In addition, most CP intervention studies have not even reported a breakdown of race or ethnicity in participants [6]. Disparities also exist in rural populations where dementia is less likely to be diagnosed, thus delaying access to supports and services for BPSD [9]. Further, the need to culturally tailor for rural populations is not generally considered despite significant cultural and social, economic, and environmental differences (Rhew et al., 2023). These disparities highlight the urgent need for innovative solutions to empower CPs with accessible, culturally tailored tools to manage BPSD effectively across populations less likely to

receive effective care and supports for AD/ADRD, and BPSD specifically.

Based on these identified disparities and additional input from community-based clinical teams and dementia support organizations, our team sought to develop the Aliviado Caregiving mobile health (mHealth) application. The application uses a precision heuristic artificial intelligence/ machine learning (AI/ML) algorithm that supports CPs to prioritize and treat BPSD through evidence-based, non-pharmacological care strategies (see Figure 1). This approach is built on the original Aliviado Dementia Care model to support clinical teams in BPSD management, which is conceptually guided by the structural model of caregiving stress [10]. The purpose of this study was to describe the iterative, human-centered design process undertaken in the development of the Aliviado Caregiving wireframes, intending to improve the app's feasibility and acceptability for future pilot testing.

Figure 1

Before and After of the Aliviado Caregiving Application and Select Features Home Page



Methods

The development of the Aliviado Caregiving app involved an iterative three-stage process to receive and incorporate feedback into the adapted wireframes. The initial wireframes were

	Stage 1 Review		Stage 2 Review		Stage 3 Review
Content Expertise	Investigator Team & Clinician Survey		CPs of Persons Living with Dementia		CP Advisory Board
Requirement	Streamlined Sign-Up Process	**Revise Wireframe**	Clarify Intended Recipients for Care Plans and Strategies	**Revise Wireframes**	Improved Empathy/Information on Machine Learning Recommendation

s for a CP Symptom Self-Management Application	Privacy & Data Protection	**s**	Reconstructed Dashboard		Further Incorporated Plain and Inclusive Language
	Identified Caregiver-Focused App Functionality for Symptom Self-Management		Ensured Inclusive Language		Reminder Push Notifications Modified
	Wireframes Developed for Internal User-Testing		Identified Relevant Caregiving Concerns		Caregiver Design Preferences and Suggestions
			Revise Wireframes		
Next Steps	Pilot Project with Informal CPs				

These three stages were guided by an iterative review and revision template and followed a human-centered design [11]. The requirements of the Aliviado Caregiving application were identified and reviewed in three stages: 1) a Needs Assessment involving an investigator team and a clinician survey, 2) a Co-design session with CPs of PLWD, and 3) with a CP advisory board (CAB). We designed and revised the Aliviado Caregiving wireframes between each review stage to address expert feedback (see Table 1).

Table 1

Aliviado Caregiving Three-Stage Review Process and Wireframe Revisions

Materials and Procedures

Stage 1: Needs Assessment by Investigator Team and Clinician Survey

The investigator team identified the minimum requirements for a CP application for symptom self-management, building on findings from our previous nationwide pragmatic trial of the comprehensive dementia symptom management program, Aliviado Dementia Care, and developed an initial set of wireframes [12]. This trial included as part of the Aliviado Dementia Care Program intervention a clinician-centered mHealth app to assist in assessing patients and supporting care partners in BPSD management. During said trial, clinicians at multiple sites remarked on the need

for empowering CP and providing a companion app for them to use to address BPSD. They also shared that CP had asked about the clinician app and why they couldn't have access when it was being used in their homes. The investigator team, therefore, surveyed clinicians from the pragmatic trial who used the clinician version of the Aliviado Symptom Management app to prioritize key potential features for developing a CP counterpart, later named the Aliviado Caregiving App. The recruitment process, eligibility criteria, and procedures of the clinician survey were published elsewhere, though results focused on usability of the Aliviado Clinician app and not development of the Aliviado caregiving app [13]. Briefly, a convenience sample of 101 clinician users completed an online Qualtrics survey between June and July 2020. In the survey, clinicians were asked to prioritize key features for the CP version of the BPSD self-management app [13]. A set of wireframes was then developed based on the key features identified by the investigator team and prioritized by clinician users to support CP BPSD self-management. These wireframes were further reviewed and co-designed with CPs and the CAB during Stage 2 and Stage 3, as detailed below.

Stage 2: Review by Care Partners of PLWD

We recruited CPs who were 18 years or older, English-speaking, possessed a smartphone, and dedicated a minimum of four hours a week to caring for a PLWD. Our recruitment strategies included registrations on TrialMatch and Clinical Trials websites in collaboration with the Alzheimer's Association after IRB approval (IRB-FY2023-7011). Oral consent was obtained, and individual Zoom interviews (approximately 30 to 45 minutes) were conducted by a trained Project Manager (AD). In addition, an optional brief demographic survey was administered. A $50 incentive gift card was given upon successful completion of the interview.

Stage 3: Review by Care Partner Advisory Board

We created a CAB using purposive sampling. We partnered with a community chaplain (DL) to recruit potential CAB members who were current or past CPs of PLWD on a rolling basis. One focus group (approximately one hour) and individual meetings with each CAB member

(approximately 30 to 45 minutes) were held virtually. CAB members received $100 gift cards for the two meetings. While the larger study received approval, this review stage did not require informed consent as it did not meet the definition of Human Subjects research but focused on app development in partnership with content experts.

Data Analysis

Descriptive statistics were calculated to summarize clinician characteristics and identify key features for display in the initial wireframes of the CP app in Stage 1. Qualitative transcripts were analyzed using reflexive thematic analysis for Stages 2 and 3. An inductive analytic process was primarily utilized to identify themes grounded in the data [14]. We present our co-design results with CPs and CAB as a synthesis by describing content expert feedback using the most prominent suggestions/changes through identified qualitative themes of the iterative review stages and representative quotes, which include participant pseudonyms. We bolded each stage in the text to make it easier to identify. Multiple discussions with the entirety of the research team were held to discuss and validate the analysis results and select illustrative quotes from a range of participants. In addition, member checking was incorporated in all three stages to ensure iterative revision and trustworthiness from the investigator team, CPs, and CAB members.

Results

Overview of Participants and Themes

Our iterative review process involved an investigator team and 101 clinician users, 8 CPs, and 8 CAB members. The Stage I investigator team consisted of professional experts working in the field of dementia care (e.g., researchers). The majority of clinician users were nurses (44.8%) and were White (74.0%) [13]. The CPs were primarily female (63%), had completed high school as the highest education (63%), and were widowed (63%). Stage II CPs were identified as White (50%), Black or African American (37.5%), or Asian (12.5%). The Stage III CAB members were primarily female (89%), and all members self-identified as Black or African American (100%). Four themes

were identified: 1) *User-Interface Design Preferences and Suggestions*, 2) *User-Friendly Language*, 3) *User-Concern Prioritization*, and 4) *Future Application Features*.

Iterative Review Process and Actions Taken by Stage

Stage 1: Investigator Team and Survey

According to clinician users, the most essential app features for the CP version were “caregiver stress management strategies/intervention” (84%), “dementia symptom management education and resources” (73%), “caregiver stress self-monitoring/tracking” (69%), and “dementia behavioral symptom monitoring/tracking” (59%). These features were discussed by the investigator team and used to inform the development of the initial wireframes for the CP app.

In **Stage 1**, the investigator team identified the need to enhance the user experience by tailoring design elements to better suit the needs of CPs of PLWD. An empathetic design approach was also recommended. In response, we incorporated greater flexibility by allowing users to replace the default name with a chosen relationship term (e.g., "father," "mother")—a change intended to honor PLWD personhood and align with social norms. Furthermore, major changes included avoiding changing the terminology of “memory loss” to “changes in thinking” to reduce stigmatization. The investigator team also advised that we update the app push notifications to “Over the next month, we’ll remind you to practice your strategies.”

Stage 2: Care Partners of PLWD

In **Stage 2**, the design enhancements made in **Stage 1** were well-received by informal caregivers, who emphasized their practical relevance and emotional resonance with caregiving experiences:

“Properly arranged to take me through the whole process. Like the way it is segmented.” (CP-6)

Informal CPs in **Stage 2** generally found the language to be appropriate in the Aliviado Caregiving app. “It seems simple, easy to maneuver, easy to understand” (CP-5). One caregiver, however, specifically noted that care plan identification needed additional information:

"Clearer message to guide me to build my care plan or go to de-escalation" (CP-4).

Feedback pertaining to user-prioritization and future application features was only present in **Stages 2** and **3**, as these topics were introduced following the completion of Stage 1. CPs in **Stage 2** found prioritizing BPSD based on their personal preferences or recommendations from the Aliviado Caregiving app to be useful. "Makes sense to me… a plan where you are able to suggest a particular plan that better works for your current situation, for both [PLWD and CP]" (CP-7). One CP mentioned,

"Now you can implement it because you have determined something [care strategy], and you have a [care] plan you can implement" (CP-2)

CPs in **Stage 2** recommended ongoing enhancement of app features to support the knowledge and care management of CPs of PLWD. For instance, one CP suggested that future versions of the app should have "More than one patient card for multiple patients" (CP-1). Another CP asked if library resources for different care strategies would be continually updated with evidence-based literature.

"Does it update current information, if I read this would I come back would it be a different article? I would want to bookmark and have new information" (CP-4).

Stage 3: Care Partner Advisory Board

The CAB members during **Stage 3** also found the design and layout appropriate, but recommended further changes. Members suggested that for older informal CPs, "the font might [need to] be bigger or bolder… because their phone it can be really tiny" (CAB-4) or "clear [instructions] but does need glasses to see] (CAB-2). In addition, CAB members also acknowledged that detailed information before beginning the questionnaires was beneficial.

"It was good to give the time, how long it will take. Because you know as a caregiver our time is limited, that is the first thing that goes through my head, half of the time if longer than four minutes I will only do half or come back" (CAB-5).

CAB members had difficulty with the app's numerically related language. For instance, the app tracks how many days were logged, and one participant was confused about what it meant,

"What is 24 days left mean? Better explain how after 28 days you will be reassessed; this should be explained" (CAB-1). Moreover, CAB members also mentioned that push notifications were beneficial, but should be less task-oriented and more motivational to encourage app utilization by caregivers. One member suggested adding,

"You are doing a good job, something to lighten it [push notification] up" (CAB-4).

The CAB members in **Stage 3** recommended that when the Aliviado Caregiving app proposes an alternative care concern, additional clarification is necessary to prevent the invalidation of the CP's subjective concern. One CP stated

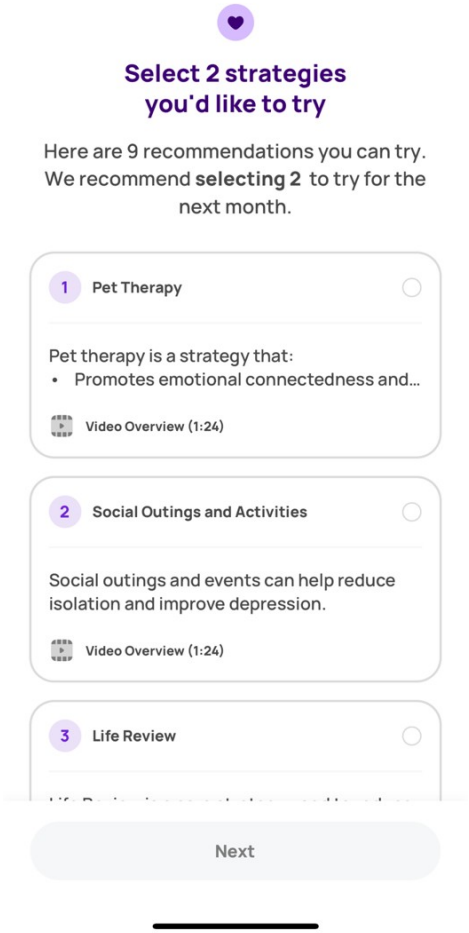
"I am dealing with this day-to-day… responding to a questionnaire, and do I doubt, or do you doubt what I am saying, based on my experience vs. your analysis [AI/ML algorithm]. Somewhere along the lines to provide explanation why the recommendation is vastly different (agitation vs sleep). How did you get here from what I told you?" (CAB-3).

CPs also mentioned that choosing two initial care concerns was difficult.

"Hard to just pick one, a lot of the concerns are a problem and a top concern. Would prefer to be able to choose top three, but also let the user know that they are able to choose more concerns on the second screen" (CAB-8) (see Figure 2 for revised wireframe).

Figure 2

Revised Care Strategy Selection Wireframe Based on Participant Feedback



The CAB in **Stage 3** offered additional recommendations for enhancing future features of Aliviado Caregiving. One member (CAB-7) emphasized the importance of developing a Spanish-language version to better serve the growing population of diverse care partners (CPs) of persons living with dementia (PLWD). Another member (CAB-5) suggested offering alternative formats for accessing logged progress, such as the ability to receive summaries via text message rather than exclusively through email:

“If there is any way to text our Summary as an option instead of just email…” (CAB-5)

Discussion

We used an iterative, human-centered design approach to develop the Aliviado Caregiving app with an investigator team and clinician survey, CPs, and a CAB. This study demonstrates how we adhered to an iterative process, implementing continuous modifications at each stage, in

collaboration with various content experts to enhance the app's development. Furthermore, the process of this study provides an example of robust community-engaged practices that include multiple types of content experts while prioritizing the needs of the intended population.

The greatest strength of this study was reducing common limitations of human-centered design in developing the Aliviado Caregiving app. Common limitations include sample bias, overreliance on early end-user input, and ethical/societal issues that may be unaddressed at the macro level when focusing on individual users [15]. First, we attempted to mitigate sampling bias by partnering with local partners and organizations, such as a community chaplain, to include a diverse sample of CPs with a range of views and contexts. Second, although our human-centered design was prolonged, our robust design process at various time points was a valuable means to implement and meaningfully design the app for end-users. In addition, we consulted not only end-users but also other key participants (clinicians and CAB), who are often underrepresented in many human-centered design studies [15]. Lastly, the rapid advancements in AI/ML applied to decision-making processes may inadvertently perpetuate algorithmic biases and health disparities in diverse populations. We utilize the formal Agency for Healthcare Research and the National Institute on Minority Health and Health Disparities Algorithm Bias Framework to guide this study [16]. The five guiding principles have played an important role in designing the Aliviado Caregiving app and informing its evolution, particularly in terms of engagement with diverse CPs during the future pilot testing phase.

The Aliviado Caregiving App holds significant potential to address the existing limitations of mHealth apps designed for informal CPs of PLWD. Most dementia care apps for informal CPs offer educational resources but are not tailored to meet CPs' specific caregiving needs [17]. We contribute to the advancement of knowledge on AI-enabled mHealth apps by developing and describing how Aliviado Caregiving may offer personalized, contextually relevant learning and support for informal CPs. Furthermore, the Aliviado Caregiving app aims to test a novel AI/ML algorithm to assist

informal CPs in identifying and prioritizing BPSD at various stages of a PLWD disease trajectory. By facilitating a more targeted and adaptable care plan that includes educational care strategies, our mHealth app has the potential to alleviate CP burden while also reducing the prevalence of BPSD.

Limitations and Future Directions

We aim to establish an effective mHealth app to support marginalized CPs to prioritize BPSD through an AI/ML algorithm and provide evidence-based, non-pharmacologic strategies outside of the healthcare system to ultimately reduce caregiver burden. The next steps include feasibility and acceptability testing of the Aliviado Caregiving app for diverse CPs in a single-arm pilot study.

Some limitations must be considered. Although we attempted to mitigate sampling bias, there are other marginalized CPs that we were not able to include. Specifically, it will be imperative to obtain the perspectives of Latino CPs to iteratively develop a Spanish version of the Aliviado Caregiving app, as this population is projected to experience a seven-fold increase in the number of PLWD by 2060 [18].

Conclusion

In this study, we have described our iterative, human-centered design of the Aliviado Caregiving app to offer an example of how we addressed common limitations to improve our mHealth app. The long-term objective will be to make the app broadly available to the general public to increase access to high-quality, low-cost NPS self-management to help achieve health equity and reduce CP burden, stress, and burnout.

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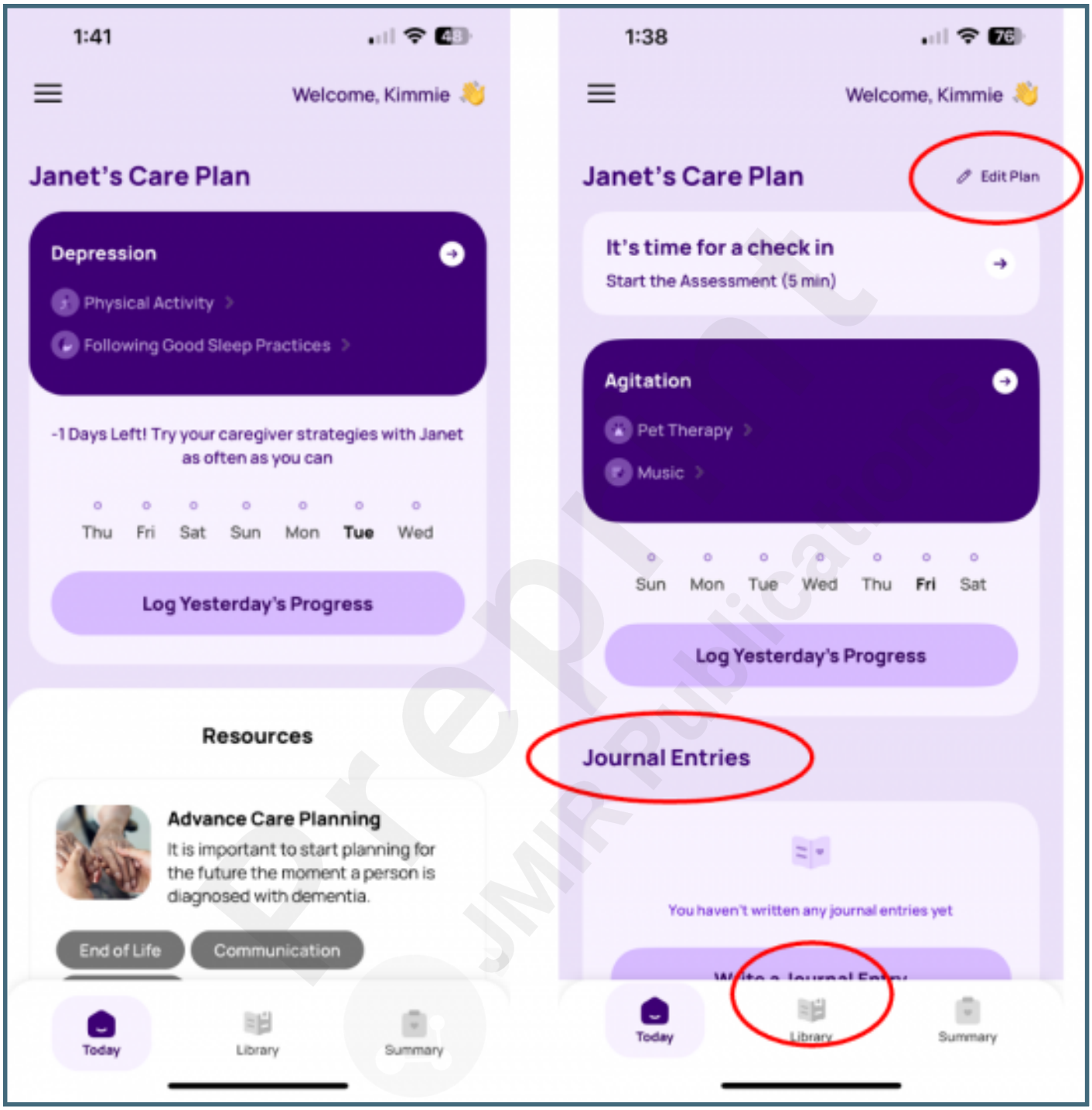
Supplementary Files

Figures

Before and After of the Aliviado Caregiving Application and Select Features Home Page.



Revised Care Strategy Selection Wireframe Based on Participant Feedback.