A qualitative approach to caregiver experience testing of an online adaptation of REACH II: GamePlan4Care

Jinmyoung Cho, Thomas Birchfield, Marcia G Ory, Alan B Stevens

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Jinmyoung Cho[1, 2] PhD; Thomas Birchfield[1] MS; Marcia G Ory[3] PhD; Alan B Stevens[1, 3] PhD

[1]Center for Applied Health Research Baylor Scott & White Research Institute Temple US
[2]Saint Louis University School of Medicine St. Louis US
[3]Texas A&M School of Public Health College Station US

Corresponding Author:
Alan B Stevens PhD
Center for Applied Health Research
Baylor Scott & White Research Institute
2401 S 31st St
Temple
US

Abstract

Background: GamePlan4Care (GP4C) is an online adaptation of the Resources for Enhancing Alzheimer's Caregiver Health II (REACH II) intervention, redesigned and reformatted for online delivery.

Objective: The goal of GP4C is to create an online family caregiver support platform that facilitates self-directed exposure to evidence-based skills-training and support for caregivers of persons living with dementia (PLWD). This multi-dimensional approach of utilizing technology enhanced with live support has the potential for improved scalability and sustainability.

Methods: In preparation for a randomized clinical trial of the new intervention, the GP4C platform underwent user interface/user experience (UI/UX) testing with caregivers as part of an iterative design process. Testing of caregivers' reactions to technical and content-related aspects of the platform was conducted with 31 caregivers recruited through partner organizations in central Texas.

Results: The thematic analysis revealed three themes: supportive resources as a common theme, a comprehensive approach for technical aspects of the platform, and active engagement for content aspects of the platform. Participants also suggested changes in navigation and content.

Conclusions: Findings from the usability testing sessions indicate that the features of the platform would be beneficial to meet the needs and provide resources for caregivers of PLWD.

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Cho J, PhD[1,2], Birchfield T, MS [1], Ory MG, PhD [3], & Stevens AB, PhD[1,3]

[1] Baylor Scott & White Research Institute, Temple, Texas

[2] Saint Louis University School of Medicine, St. Louis, Missouri

[3] Texas A&M School of Public Health, College Station, Texas

Corresponding author: AB Stevens, alan.stevens@bswhealth.org

Contributions:

All authors meet authorship conditions 1, 2, and 3.

ORCID:

J Cho: https://orcid.org/0000-0002-5836-2368

T Birchfield: https://orcid.org/0009-0003-7932-9588

MG Ory: https://orcid.org/0000-0001-8036-2383

AB Stevens: https://orcid.org/0000-0003-2247-1228

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Keywords: Dementia caregivers, User interface/User experience (UI/UX), Technology, Online caregiving program

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Communities across the United States are challenged to meet the physical, emotional, and social needs of persons living with dementia (PLWD). Currently, nearly 7 million Americans are living with dementia, and that number is expected to almost double in the next 25 years[1]. While efforts to increase the availability of formal health and social care services are essential, support of family caregivers is paramount if they are expected to continue to provide the vast majority of daily care and support of PLWD. As reported in the National Academies' report, Families Caring for an Aging America, nearly 70% of caregivers in a nationally representative survey had provided 2 to 10 years of care, and 15% had already provided care for more than 10 years at the time of the survey[2]. In other words, an average person in their fourth decade of life is expected to eventually spend 5.0 years (or 10% of their remaining life) caring for an older adult, a situation known to have negative consequences[2]. This is significant because caregivers are more likely than noncaregivers to suffer negative consequences on their well-being such as increased depression, anxiety, burden, social isolation, and family conflict[3-5].

The negative consequences of caregiving, however, can be mitigated by engaging caregivers in programs that increase their dementia care skills while providing emotional and tangible support. A recent systematic review shows that caregivers are more likely to engage in and benefit from multicomponent interventions that assess the caregiver's challenges as well as their emotional response to providing care[6]. These considerations respect the unique circumstances of each family caregiving situation and lead to a tailored program of education, skills training, and support[7-9]. While caregiver interventions that use a tailored approach to education, skills training and support exist, services derived from these evidence-based interventions are not routinely provided by health and social support organizations. Two major barriers to the provision of such services include the cost of developing a workforce trained in evidence-informed dementia care strategies and the lack of formal payment systems (e.g., commercial insurance, Centers for Medicare and Medicaid Services, CMS)[10-12].

Internet-based techology (i.e., online) provides an alternative approach for moving evidence-based interventions into widely available caregiving education, skills training and support programs. Online caregiver support programs have the potential to increase the availability of caregiver interventions that have previously been delivered through an in-person/telephone format[13, 14]. Moreover, internet-based technology can be designed to meet the expressed desire of caregivers for an on-demand, self-paced, learning and skills training experience to support their role as a dementia caregiver[15]. Use of internet-based technology in the provision of existing evidence-based interventions is supported by research on caregiver interventions designed for internet delivery[16-19].

Multiple meta-analyses of caregiver interventions designed for internet delivery have shown promise, but findings have been mixed[13, 20-22]. Some reviews found that technology-based interventions were just as effective as face-to-face interventions; however, mixed delivery methods showed greater improvements than web-based, telephone or DVD-based interventions alone[21]. Leng and colleagues found that personalized internet-based interventions had a greater effect size than nonpersonalized interventions on depressive symptoms and perceived stress[13]. These findings suggest the need for more attention to the engagement of family caregivers in the design and user testing of online platforms for dementia caregivers.

To address this need, the research team created an online family caregiver support platform, GamePlan4Care, by applying technology to an existing evidence-based intervention (i.e., Resources for Enhancing Alzheimer's Caregiver Health, REACH II). This study explored the usability of GamePlan4Care among family caregivers of PLWD.

GamePlan4Care (GP4C): An online adaptation of REACH II

GP4C incorporates a risk-based approach and aligns the self-reported needs of a caregiver with therapeutic content consistent with the REACH II domains of safety, stress, health, emotions, care services, support, and behaviors. Similar to REACH II, the GP4C therapeutic strategies include educational materials, tools (e.g., worksheets), skills training exercises, and access to peer support. Importantly, the online format of GP4C allows strategies to also be presented in video format, which was not done in REACH II. The therapeutic process is facilitated by a Dementia Care Specialist, a trained interventionist who assists the caregiver in the navigation of the online content and personalized goal setting via telephone and email support.

After an initial build of the platform to include the functionality of an initial assessment of the caregiving situation followed by access to the Safety and Emotions domains of the GP4C content, we conducted caregiver usability testing on these domains to identify additional design needs in preparation for a randomized trial. This manuscript describes the caregivers’ experience in using the initial design of the GP4C platform and key aspects of how they experienced the functionality of the platform regarding the initial assessment and tailored education and skills training on the two domains of GP4C: Safety and Emotions.

Methods

Process

The GP4C research team worked with a large integrated health care system’s Digital Health Development team to develop a task hierarchy cataloging individual tasks to accomplish within the platform and salient design questions appropriate for experimenter prompts. The research team conducted usability testing concurrently with content enhancement via a method of iterative evaluation using the think-aloud technique[23]. This method characterizes the ease in which a user can complete a task, by what means a user attains mastery of system features, and problems a user encounters while using the system. Such tasks included registering, logging in, answering user assessments, and navigating to education and skill-building content (Table 1). Participants tested either the technical-related aspects (user interface and design) or content-related aspects (wording/appropriateness of questions and feedback, satisfaction with education and skill-building content) of the GP4C platform. User testing sessions for each participant were audio recorded. Participants performed system tasks while vocalizing their thoughts, feelings, and satisfaction with the platform. Research staff prompted the participant with a question to elicit specific feedback regarding that feature. Upon completion, participants also provided their overall impression/opinions regarding their experience with the platform.

Table 1.
Summary of tasks that were tested by the participant.

Technical-Related Aspects	Content-Related Aspects
- Logging into the platform	- Logging into the platform
- Responding to and submitting assessments	- Reviewing two core skill videos
- Managing messaging feature	- Reviewing three related exercise videos
- Reviewing automated feedback	- Reviewing materials, including worksheets
- Assessing video content	
- Managing goal progress	

Participants

Participants for the usability testing were recruited through referrals from local partner organizations (Alzheimer’s Texas, Central Texas Area Agency on Aging) from October 2019 to February 2020. A total of 31 caregiver participants completed the sessions, 18 were recruited to complete user testing of the technical-related aspects of the platform and then an additional 13 were recruited for testing of the content-related aspects. Tables 2 and 3 summarize the demographic characteristics and caregiving experience of participants. A majority of participants were female (87.1%) and white/Caucasian (83.9%). The average age of participants was 62 years old (range: 31-86). Nearly a third of participants were Hispanic. Caregivers were providing care to a variety of family relations with a majority being parents (-in-law) or spouses.

Table 2.

Demographic characteristics of participants (N=31).

Participant Characteristics	N (%)
Age (mean, *sd*)	62.0 (12.2)
Gender	
Female	27 (87.1%)
Male	4 (12.9%)
Race	
White/Caucasian	26 (83.9%)
Black/African American	3 (9.7%)
Other/More than one race	2 (6.5%)
Hispanic ethnicity	10 (32.3%)
Marital status	
Married/Living as married	20 (64.5%)
Widowed	2 (6.5%)
Divorced/Separated/Never married	9 (29.1%)
Employment	
Full-time	8 (25.8%)
Part-time	2 (6.5%)
Homemaker	2 (6.5%)
Retired	13 (41.9%)
Other	6 (19.3%)
Relationship to care recipients	
Parents (-in-law)	15 (48.4%)
Spouses	11 (35.5%)
Brother, Grandfather, Friend	5 (16.1%)

Participants reported that almost half of care recipients were diagnosed with either Alzheimer’s disease (41.9%) or dementia (48.4%). Over 80% of caregivers were living with the care recipient (12.9%) or living nearby (less than 15 minutes; 71.0%). Most participants also reported providing over 20 hours of either indirect or direct care weekly for at least two years.

Table 3.

Caregiving experience of participants.

Caregiving Characteristics	N (%)
CR[a] diagnosis	
Alzheimer’s disease	13 (41.9%)
Dementia	15 (48.4%)
Vascular dementia or TIA[b]	4 (12.9%)
Parkinson's disease	2 (6.5%)

Lewy-body disease/Fronto-temporal disease	5 (16.1%)
MCI[c]	2 (6.5%)
Distance to CR	
Living with CR	4 (12.9%)
Less than 15 min	22 (71.0%)
Within 15-30 min	1 (3.2%)
Within 1 hour	4 (12.9%)
Indirect care hours per week	
Up to 8 hours	1 (3.2%)
9 - 19 hours	2 (6.5%)
20 -39 hours	3 (9.7%)
40+ hours	23 (74.2%)
Direct care hours per week	
Up to 8 hours	1 (3.2%)
9 - 19 hours	5 (16.1%)
20 - 39 hours	10 (32.3%)
40+ hours	15 (48.4%)
Caregiving duration	
6 months - 2 years	9 (29.0%)
2 - 5 years	13 (41.9%)
5+ years	9 (29.0%)

[a]CR: care recipient

[b]TIA: transient ischemic attacks

[c]MCI: mild cognitive impairment

Analysis

Analysis of the data was performed using an inductive thematic analysis approach[24] with 31 transcripts. The research team focused on participants' progress on the tasks and their valuable feedback on their experience as they completed the tasks. Participants were observed, vocalized what they were thinking and feeling, and then provided final feedback after completion of the tasks. All of this information was trangulated to determine the users' experience with the platform[25].

Computerized transcripts were reviewed initially for quality assurance by research staff. Two researchers completed the thematic analysis. Both researchers independently reviewed the transcripts and revisted the recorded audio of participants completing the tasks. Initial ideas were documented and discussed during the initial phase of data familiarization. The coding phase of the data was then initiated. Key terms (words and short or long phrases) were identified to illustrate the concepts of the caregivers' experience and feedback found in the transcripts and were saved in an excel spreadsheet.

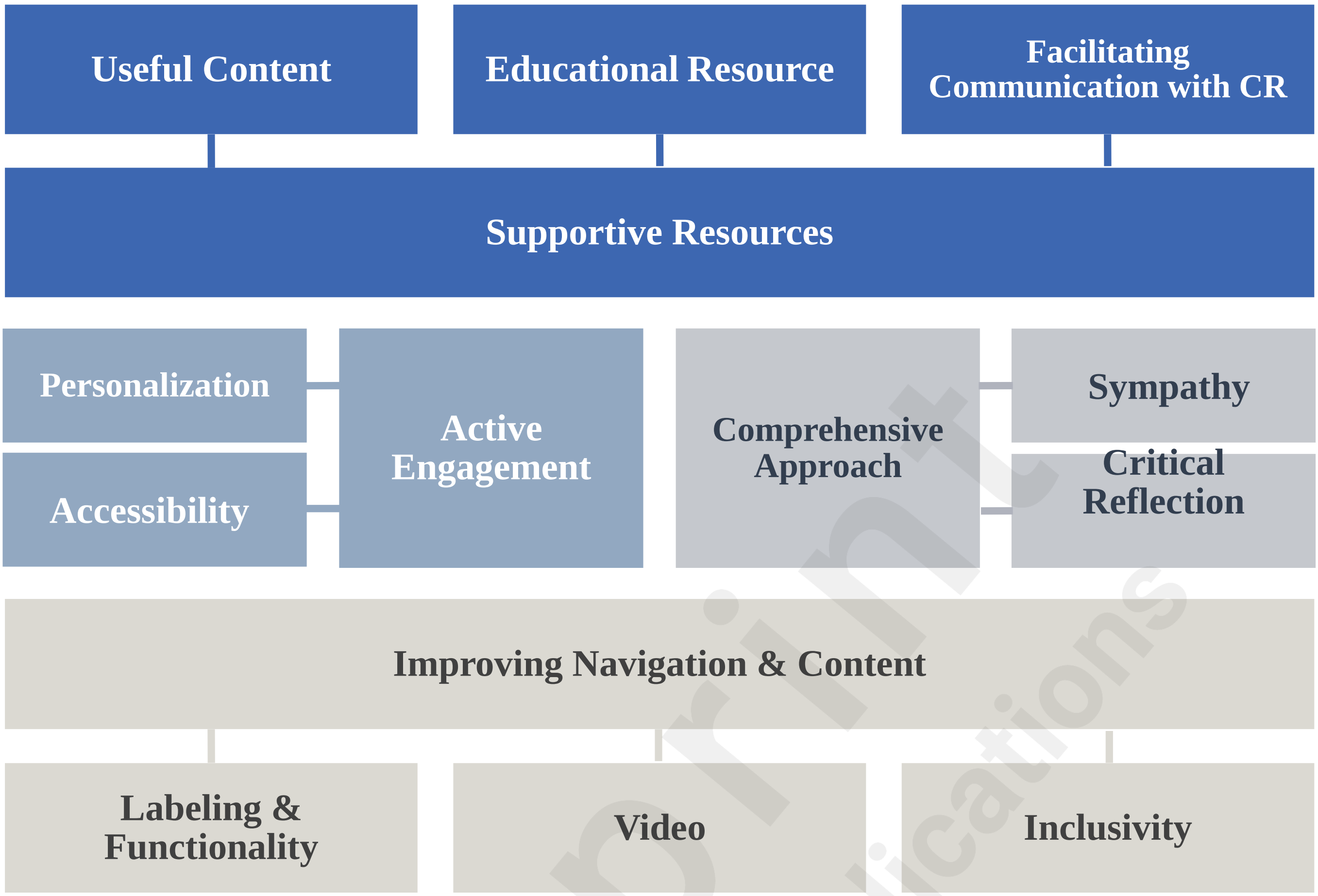
Key terms were discussed over multiple meetings. Once agreement was reached on the key terms, they were brought to the full team for further discussion. These key terms represented underlying ideas from the data that the research team considered pertinent to the aim of the study. The third stage consisted of formulating themes by grouping together key terms that reflected similar overarching ideas. Common themes from technical and content-related aspects and a major theme specifying each aspect emerged. Additionally, participant suggested themes also emerged. Under each major theme, subthemes related to the main theme, but separate and distinct enough to be differentiated, were also revealed. Major themes and subthemes applied to the data were defined and labeled. Finally, examples were chosen from the transcripts to illustrate theme elements.

Results

Overall, many participants seemed satisfied with the quality of the content and flow of the platform. One participant said *"Oh, it is very clear and understandable…"* Another participant commented that *"it [videos] weren't exhausting or boring."* Another participant felt that the videos *"…are very clear, very simple, they are not overwhelming, they are not over my head, so it is good."* Several other participants also commented that the videos were *"very soothing."* A participant also mentioned that they thought the videos would be used by caregivers to refer back to when brainstorming different strategies to use with the care recipient. An overview of the themes and subthemes is presented in Figure 1.

Figure 1.

Summary of major themes and subthemes of the data. Note: Main themes are underlined. CR: care recipient.



Common Theme: Supportive Resources

In addition to the general positive responses, all the participants agreed that the platform provided very supportive resources for their caregiving responsibilities. Caregivers described the content as useful and educational, suggesting that the platform would be beneficial to facilitate their caregiving tasks and communication with their care recipients.

Useful Content. Participants felt that the content was appropriate. When they were asked to review the safety topic in particular, some caregivers seemed to agree that the safety tips on driving are an important strategy that they should address with their care recipients. For example, one caregiver said, *"It is very clear that there is going to be some strategies and…hints to help the caregiver."* Another participant noted *"I am liking what it says. This is a reminder of what I need to be looking for."* Similarly, another participant explained *"It is not too long, yet it is very informative."* Another participant echoed a similar perspective by saying *"I think this is very good* *as far as different topics and stuff."* Another participant commented that the content was *"conversational"* and that they liked the *"vocabulary"* used throughout the platform. One participant expressed that they felt the videos were useful, they said *"…reading something is one thing, but to have the video show, it just really keeps your mind, you know, wanting to continue."*

Educational Resource. Several participants commented that the program would help them persist with caregiver education. For example, one participant said *"It is not something I would just watch and put it away. I could have these printed out in my little book."* Another participant stated, *"I like how they are almost making it [the program] like a continuing education."* Similarly, another participant said, *"It's not too long, it gives information, it makes me want to come back and see what else is there."*

Facilitating Communication with Care Recipients. As many participants recognized the materials as helpful and educational, a participant commented that the worksheets could help facilitate difficult conversations with the care recipient and help them decide on changes together.

> *So, to discuss those worksheets…that's another good reason for worksheets… I'm saying I feel like I'm always the one to having to say no you can't, no you can't, and so the person receiving care, this is a way… to say we're going to go through this and we're going to help you identify what things are safe for you, what you feel comfortable with and what you may not. So, it's a platform that opens up the communication with that individual to try to keep them safe as it relates to driving.*

Technical Theme: Active Engagement

Participants noted that they appreciated the active engagement required for dementia caregivers. One participant said that they liked *"That you are actually trying to do something to help the caregivers out there rather than just saying oh you got a local support group down the street."* A caregiver also mentioned that she appreciated she could access the information on her own time. She said *"…it is giving you support where there is nothing expected of you, you know you don't have to* *come back and do 20 visits, it is all online when you have time."* Another participant felt similarly and said *"I like the thought of tutorials that I can go through and work on myself at my pace and all that."* The feature that the information was gathered and organized in one central location was appreciated. For example, *"I see this [is] very unique and different than I've accessed so far, and I've been doing a whole lot of research…I've been online for weeks and week and weeks now, so this is definitely something that I think will be used a lot…"*

Personalization. Participants liked the level of personalization. For example, after entering information about the care recipient, caregivers would go on to receive questions that included that relationship (e.g., "your mother"). One participant said *"the most positive are definitely the suggestions that strictly apply to me from what they heard from my answers."* Similarly, another participant said *"It is nice to know that they have recognized my answers."*

Accessibility. Participants also seemed to appreciate that they could connect with a professional (i.e., dementia care specialist) for additional help, especially in times of crisis. A participant said *"It would be good to have [a dementia care specialist], as a caregiver you get flustered with everything and bogged down with everything and you cannot think correctly sometimes because you are overwhelmed with trying to figure out how to fix the situation."* Another participant said *"I think that that's important, but there are some times where you just feel alone because there is nobody out there who gets what you are going through…and you have a specialist out there who is willing to listen without judgement…"* One participant also stressed the importance of a care specialist (or other professional) providing thoughtful and specific feedback when reviewing information that had been completed on the platform. They said *"I would want to know that somebody was reviewing and understanding what my situation is. I wouldn't want somebody to be, you know, just looking at it and doing a cursory review."*

Content Theme: Comprehensive Approach

The themes from content interviews/sessions can be divided into two subthemes: sympathy and critical reflection. Caregivers expressed that the features of the platform resonate with their experience.

Sympathy. A participant appreciated that the topic they visited (i.e., caregiver guilt) was featured in the videos, which resonated with their experience. The participant explained *"I'm very happy to hear that guilt is something that they are definitely touching on…guilt is a big part, and as a caregiver, you can find yourself going down that road…very quickly."* Another participant also appreciated that addressing caregiver guilt was included in the platform. The participant said, *"I like that [it's included] because…sometimes you feel guilty and it's just a little bit, but sometimes you feel guilty and it's extreme."*

Another participant agreed and said, *"When I feel guilty I feel like God how can I be tired or I will think to myself…you know she took care of you and lot of thoughts…but maybe [I] felt ashamed because I felt that and then of course I felt sorry."* Similarly, another participant commented that *"Another thing…that needs to be said here is that you're going to have negative feelings and you're going to have the negative responses, and you have to learn to forgive yourself. I think because in the sense telling me I shouldn't have the negative thoughts increases my guilt."*

Critical Reflection. Caregivers also felt that the videos did a nice job of helping caregivers think critically about their choices. A participant said, *"…it makes you think where can they drive, what do I cut out first."* Another participant commented that the video made them think differently about their emotions. The participant said, *"sometimes I think 'mom, are you just playing with me?'…they are not, you just got to be patient and then the second part of it about the guilt in that, that really makes you think and makes you analyze yourself."* Several caregivers also noted that they appreciated that the videos reminded caregivers that they could not change the care recipient. A participant said,

> *"So, I also very much appreciate the way that they are subtly reminding the us as caregivers that the person with dementia cannot change and that is a very big part of*

> *dealing as a caregiver for with someone with dementia and Alzheimer's is that they don't know how they are and have to be…to remind yourself this is not who the person was. This is who they are now, and they cannot change it. So, I like seeing that in here.”*

Participant Suggested Themes: Improving Navigation and Content

As a main goal of the tasks, participants provided feedback on how to improve the platform features and contents. Three areas of improvement were identified: labeling and functionality, video, and inclusivity.

Labeling and Functionality. Clearer labeling or using different colors on the platform was suggested by several participants. For example, incorporating a *“box that says next”* rather than just an arrow. Another participant suggested *“the button area and the fonts”* could be bigger. Another participant suggested making completed sections “*a different color than the rest*” and several participants mentioned that they were color blind and had a difficult time seeing text show up. The participant said *“…I’m color blind, so text itself, I can’t tell what that looks like until I go to the box.”* However, other participants commented that they liked the colors that were used. One participant said *“Oh, I like all the blue and gold and stuff like that. I think they are very soothing to the eye. The whites good because you need to make everything else pop up on the screen better. I mean, I think this is good because at least the dark blue highlights all the stuff over here.”*

Video. One of the few criticisms of the videos was given by a participant who felt that the videos were *“a little slow in some parts.”* However, another participant disagreed and felt that at times the narrators in the video were *“speaking a little fast.”* Another participant suggested that the video reflections have more parameters. For example, they suggested that the video narrator say, *“tell me what you’re thinking in two sentences”* rather than *“what are you thinking?”* One participant felt that the video narrator should introduce themselves each time and provide a brief overview of the topic. The participant felt this would be particularly helpful when caregivers were skipping around the site. They said *“…maybe you need to … tell what you’re going to talk about.”*

Inclusivity. Participants addressed the importance of making sure the materials were inclusive for a wide range of individuals. For example, a caregiver also noted that cost efficiency is important when creating any materials that caregivers are expected to print. The caregiver said, *“I have to control cost in the household, because I'm looking at hiring people to come in, so if I can print this, even though this looks pretty, if it would print in black only without me having to do anything, then that would be great because this is extra ink and cost.”* Another participant mentioned concerns about how a caregiver might access materials, particularly if *“some of the [computer] software is really, really old.”* The caregiver went on to explain that if it was too complicated, caregivers would likely not download the worksheets and that *“technical support”* may be useful for some caregivers. One participant also mentioned the materials were needed for individuals who didn’t speak English. The participant said *“…within the United States there are many Spanish-speaking individuals, so at some point certainly should be translated…”*

Discussion

This study presents participants’ experiences from user testing of GP4C, an online adaptation of the REACH II caregiver intervention. User inferface/user experience (UI/UX) testing is an essential first step before finalizing one’s digital tool[26-28]. Similar to other usability studies[29, 30], we explored both content- and technology-related aspects of our platform. We focused on the way participants experienced and reacted to the GP4C platform while completing their tasks. Results showed that GP4C was appreciated by participants because it offered a unique resource for those who provide care to a PLWD. In general, participants recognized the platform’s comprehensive approach refecting their experience as caregivers. Active engagment including personalization for their own needs and accessibility to resources such as the Dementia Care Specialist intervention staff were emphasized as the best features of the platform. After completing tasks with the platform, participants provided valuable suggestions to improve navigation and platform content. Thus, the overall positive responses from participants were promising and encouraged the research team to move forward in finalizing the platform.

Lessons learned for the platform development/user-informed platform changes

The qualitative feedback was used by the research team to update the platform. The following design changes were implemented in the final iteration of the GP4C platform.

Navigation and basic layout: Based on user feedback, the research team worked with the development team to change the navigation and basic layout. For example, the platform included explict buttons of “Next” and “Back” which were resized and recolored to increase visability, callouts (e.g., “new message”) were added to explictly capture the caregiver’s attention, and clues (e.g., images, spinners, and prompts) were added to make workflow and progression more smooth.

Assessment items and response choices: Not surprising, the participants preferred a conversational tone in assessment items and real-life reflective responses. For instance, one assessment question was changed from “How severe are the dementia symptoms?” to “How would you describe his/her thinking and memory changes?”and one of the choices to the question, “Does he/she drive?” was changed from “Never” to “Never, or not anymore”.

Tools to orient user to site and its use: Some participants, especially older caregivers, were frustrated with the newly developed interface because they were not familiar with it. To assure simplicity and logical progression of the interface, the platform added more tools to assist caregivers (e.g., welcome video presented upon first visit to user dashboard, opening and closing scenes to remind users how to start and complete goals, and demonstrations of live use of worksheets).

Limitations

This exploratory usability testing is not intended for generalization but rather to provide user feedback to a specific digital health tool. Thus, a limitation of the present study may be its lack of representativeness in the sample and generalizability to a broader population. The participants of the study were recruited from one geographic area of the United States. Other caregiver populations in different regions might present different opinions due to their accessibility to local resources and support. Next, the themes identified and presented in this study were identified in the midst of the GP4C platform development. Participants were only allowed to visit portions of the domains (i.e., safety and emotions) rather than the full platform. This was because the iterative design resulted in updates being made to the platform as the usability testing was being completed. We acknowledge that participants may express different opinions on the final version of the platform if they were able to visit all of the domains. Despite these limitations, this study provides a model for conducting usability testing of online caregiver support programs with the end user.

Conclusions

This study presented the first stage of the development of GP4C, an online family caregiver support platform. Usability testing and participants' in-depth and positive feedback showed its functionality and utility as a potential caregiver support program for dementia caregivers. The research team finalized the platform based on these results and is currently conducting a randomized clinical trial to show the effectiveness of the platform.

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Conflicts of Interest:

No conflicts of interest to disclose.

Abbreviations:

GP4C: GamePlan4Care

REACH II: Resources for Enhancing Alzheimer's Caregiver Heath II

PLWD: Persons living with dementia

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Supplementary Files

Figures

Summary of major themes and subthemes of the data. Note: main themes are underlined. CR: care recipient.