

Examining the Clinical Workflow and Outcomes of Integrating Health IT to Educate and Support  
Dementia Caregivers

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## Abstract:

**Purpose:** Care for people living with dementia (PLwD) is complex and deficits in information gathering and communication between caregivers and providers can have a negative impact on caregiver mental health as well as clinical decision making. **Scope:** This study tested a newly-developed web application, called *CareHeroes* that is multi-functional. The app provides caregiver education and support and allows for the tracking and sharing of clinical information about the care recipient between caregivers and providers. **Methods:** Caregivers and clinicians at two memory clinics (Miami, FL; Birmingham, AL) were recruited and asked to use *CareHeroes* for a 12-month period. Assessments of caregiver burden, depression, and self-efficacy were assessed at baseline, 3-months, 6-months, and 12-months. **Results:** Due to the COVID-19 pandemic, there were challenges in recruiting caregivers for the study and due to attrition, evaluation of caregiver outcomes was limited to only 3-month follow-up. There were no statistically significant changes observed for depression, burden, or self-efficacy. However, it is not clear how the COVID-19 pandemic may have impacted caregiver mental health during the study period. In addition, the pandemic caused numerous challenges for clinic providers, making it difficult to integrate the use of *CareHeroes* into their daily clinic routine. More research is needed.

*Key Words: Alzheimer's disease, Caregivers, Dementia, Digital technology, Healthcare delivery*

## Purpose

The overall purpose of this research study was to integrate a new digital technology that supports caregivers of people living with dementia (PLwD), called *CareHeroes*, into clinical care at two memory clinics and evaluate its impact on caregiver and provider outcomes. These two memory clinics (Birmingham, AL; Miami, FL) collectively serve several disadvantaged populations, based on race, ethnicity, socioeconomic status, and rural dwelling.

There were two major aims of this study:

- **Aim 1.** Evaluate the impact of integrating *CareHeroes* into clinical care on clinical workflow and decision making within two health care settings.
- **Aim 2.** Evaluate the impact of using *CareHeroes* on care self-efficacy and AD-specific knowledge among dementia caregiving populations that are diverse in race/ethnicity, and community settings (rural, urban).

## Scope

### Background

In 2022, more than 6 million Americans have Alzheimer's disease or a related dementia (ADRD), most of whom live within community settings where they are cared for by family members, friends, or other unpaid caregivers.<sup>1</sup> Caregiving and clinical care for people living with dementia (PLwD) is often compromised and costly, with medical costs projected to increase from \$321 billion in 2020 to just under \$1 trillion in 2050.<sup>1</sup> A significant challenge in ADRD care relates to collecting the health information needed for clinical decision making, due to patients' communication problems associated with ADRD, insufficient time to collect relevant patient information from caregivers during the medical visit, and lack of communication with in-home health and support providers.<sup>2-7</sup> The cognitive problems associated with ADRD also

compromise shared decision making with patients, and in most cases the caregiver will make final medical decisions either alone or in collaboration with the care recipient.<sup>8</sup>

In addition to challenges in clinical care for PLwD, caregivers also experience a myriad of challenges. These include challenges in communicating with the care recipient's provider, overwhelmed coping skills, managing the symptomology of care recipients, lack of support for caregiving, and low utilization of supportive services.<sup>1, 8</sup> Due to the stress and burden of ADRD health management and care coordination, caregivers often experience physical strain, burden, and depression that may lead to institutionalization for persons with ADRD<sup>9</sup> and resulted in twice the average out-of-pocket healthcare costs in 2021, compared to non-caregivers.<sup>1</sup>

Some populations experience additional challenges and barriers in managing ADRD. African Americans and Latino/a populations are more likely than non-Latino whites to be impacted by ADRD.<sup>1</sup> African American and Latino/a patients are also more likely to be undiagnosed or receive a misdiagnosis, compared to non-Latino white patients.<sup>10-11</sup> It has also been found that African Americans with ADRD are more likely to visit the emergency department or utilize ambulance services, compared to non-Latino whites.<sup>12</sup> For caregivers, African American dementia caregivers are more likely than non-Latino white caregivers to provide care more than 40 hours per week, experience poor health, have reported a lack of understanding of ADRD before their loved one was diagnosed, and have reported dissatisfaction with their interactions with healthcare professionals to address ADRD care.<sup>13-15</sup> There are also regional disparities related to ADRD care and outcomes. For caregivers living in rural communities, there are also significant barriers, such as inaccessibility and long distances to services.<sup>16-18</sup>

Technology-based interventions have been recognized for their potential in supporting dementia caregivers and increasing quality of dementia care.<sup>19-20</sup> Technology may also help overcome barriers to disseminating existing dementia caregiver interventions that have shown effectiveness but are costly to administer in person, burdensome, or difficult for busy caregivers to participate in.<sup>21-22</sup> Over the past decade there has been an increase in the number of information technologies (IT) developed to support and educate caregivers in an attempt to increase knowledge about ADRD, improve caregiving self-efficacy, and/or to reduce depression and burden.<sup>23-25</sup> However, many existing technologies have limited functions for the complexities of caregiving, are not designed to be integrated into clinical care, and are under-researched, especially among underserved populations.<sup>23-25</sup>

### **Context: The *CareHeroes* Application (App)**

To address these challenges, our multi-disciplinary team has developed *CareHeroes*, a web-based and mobile-enabled app that is multi-functional:

- (1) it allows dementia caregivers to collect and track patient-related psychosocial data that is not typically collected through traditional electronic health record systems;
- (2) it offers a secure platform for communicating patient-related information among Dementia caregivers and providers; and
- (3) it educates dementia caregivers on ADRD symptomatology and with information, resources, and services to support dementia care and caregiving, which caregivers often are unaware exist.<sup>22</sup>

*CareHeroes* was developed in partnership with dementia caregivers, physicians, and home care providers. The team has made particular effort to develop the app using input from caregivers living in rural settings and/or those from underserved racial and ethnic groups, populations that are often digitally underserved. The team's prior market analysis of Smartphone apps targeting

dementia caregivers revealed that at the time of this study *CareHeroes* is the most comprehensive app of its type, the only app that is designed to link caregivers with providers, and the only comprehensive app available in Spanish.<sup>26</sup> Overall, *CareHeroes*' features address a number of AHRQ priorities, including: harnessing data and technology to improve health care quality and to provide a 360-degree view of ADRD patients; increasing health literacy; and promoting shared decision making. More detail is provided on the *CareHeroes* app in the Methods section in this report.

### **Previous Feasibility Testing**

In Spring 2015 a pilot study was conducted to evaluate the usage, feasibility, and satisfaction with the *CareHeroes* web/app platforms with funding from the State of Florida Department of Health.<sup>22</sup> In partnership with United Home Care in Miami-Dade County, triads of dementia family caregivers (N = 10), their assigned geriatric case manager (N = 6), and the care recipient's primary care provider (PCP; N = 5) were recruited to participate. During the 11-week intervention period, caregivers were asked to use *CareHeroes*, case managers and PCPs were asked to review available information on *CareHeroes*. Multiple data sources were triangulated, including *CareHeroes* usage, survey, and focus group data. Overall, the pilot data demonstrated that participants were mostly satisfied with the multiple features, accessibility, and usability of the app. Specific findings on the app's efficacy include: (1) Over the study period there was a total of 349 actions made on *CareHeroes*, with caregivers responsible for 85% of actions (N = 297); (2) caregivers improved their confidence in problem solving about ADRD care and were satisfied with the features on *CareHeroes*; (3) caregivers most often accessed educational resources, tracked the PWD's symptoms, and conducted self-assessments; (4) case managers reported that the app was easy to use and helpful to Dementia caregivers; and (5) 75% of the PCPs believed that *CareHeroes* would improve their communication with caregivers and other providers.<sup>22</sup>

Following the feasibility pilot study, the research team revised the *CareHeroes* app and planned for a larger pilot to test usability and outcomes when the app was integrated into clinical care for a longer period of time. This undertaking represents the current study.

### **Setting: Two Memory Clinic Units**

The research team integrated *CareHeroes* into two memory clinic settings that serve multiple vulnerable patient and caregiving populations. Memory Clinics (also referred to as Memory Centers) are outpatient healthcare facilities dedicated to screening, assessment, diagnosis, and management of cognitive disorder. Memory clinics often include multidisciplinary teams, participate in cutting edge research, and some are affiliated with universities or academic medical centers.<sup>37</sup> Memory clinics also provide education and support for dementia caregivers, exchange of information with other care providers, refer for community based services, and health promotion.<sup>37</sup> Although memory clinics provide specialized care for PLWD, there are barriers to accessing memory clinic care in addition to a national shortage of geriatric psychiatrists and neurologists.<sup>38</sup>

**South Florida Site.** The MIND Institute at Miami Jewish Health (MJH), led by Dr. Marc Agronin, is a mental health and memory clinic located on a 22-acre campus in Miami Dade County, serving urban south Florida, which is racially and ethnically diverse. The MIND Institute was recently designated by the Florida legislature as a state memory disorder clinic and serves 500 new patients per year, who average 88 years in age and are racially/ethnically diverse (80% Caucasian, 20% African American/Caribbean American, 25% identify as Latino/a). The MIND

Institute completes 4,000-5,000 patient visits per year for memory, mental health services, and/or clinical research. Patients are seen 5 days a week in the Mind Institute and are required to attend their initial office visit accompanied by a caregiver. All staff members are bilingual. There are 2 geriatric psychiatrists, psychologist, and a social worker on-site.

**Central Alabama Site.** The UAB Memory Disorders Clinics (MDC) is part of the UAB School of Medicine, Division of Memory Disorders and Behavioral Neurology, and is located in a region with large rural and African American populations. Dr. David Geldmacher leads the effort of three neurologists, and three nurse practitioners who provide ongoing clinical services. MDC is the only interprofessional MDC program in Alabama and conducts patient care sessions 5 days per week, totaling over 2,300 patient visits per year. Based on referral patterns, about 10% of the patients served by MDC are African American. Due to geographic isolation in rural areas, some ADRD patients/caregivers travel three hours or more to the UAB clinic for services (some as far as Mississippi). Also, Alabama has the 3rd highest mortality rate for individuals with ADRD: 54.2 per 100,000 patients in 2019, compared to 37.0 nationwide.<sup>1</sup> Most notable about both partnering sites is that they emphasize the needs of caregivers by providing numerous programs that focus on ADRD caregiving and family well-being.

### **Study Participants**

There were two participant groups involved with this study: health care providers and dementia caregivers. Providers were included if they provided healthcare services at one of the two clinic sites to patients with dementia. A total of eight (UAB: N = 6; MJH: N = 2) providers participated across the two clinic sites, representing several healthcare disciplines, including neurologists, geriatric psychiatrists, nurse practitioners, and a social worker.

To participate, caregivers had to provide ongoing, unpaid care to an older adult receiving ongoing clinical services at one of the two memory clinics. To be eligible, they had to: have regular access to the internet (via computer or smartphone) and telephone; be 21 years-old or older; be providing caregiving activities (Activities of Daily Living and/or Instrumental Activities of Daily Living) for an average of 2 hours or more per day of direct assistance or supervision for a person with ADRD; be able to speak and understand English or Spanish; and have the ability to provide informed consent. Generally, caregivers in the study were the legally authorized representative for the patient and would be the person to accompany the patient to their medical visits at the clinic.

A total of 21 caregivers initially enrolled in the study. Thirteen (N=13) caregivers cared for someone receiving services at MJH and eight (N=8) cared for a patient at MJH. Overall, participants were most likely to be a non-Latina white woman caring for a spouse or parent, though 14.3% of the sample included African American/Afro Caribbean caregivers and 23.8% identified as Hispanic or Latino/a. Caregivers tended to have moderate to higher incomes and more than two-thirds (68.2%) had a bachelor's or graduate degree. Most participants lived in urban (40.9%) or suburban (50%) communities. Table 1 provides detailed information about the demographics for participating caregivers.

**Table 1. Demographic Characteristics of the Caregiver Participants**

<b>Characteristic</b>	<b>N (%)</b>
Gender	
Female	18 (85.7%)
Male	3 (14.3%)
Average Age (Range)	
Race	
White/Caucasian	18 (85.7%)
African American/Afro-Caribbean	3 (14.3%)
Ethnicity	
Hispanic or Latino/a	5 (23.8%)
Not Hispanic or Latino/a	16 (76.2%)
Household Income	
Less than \$20,000	1 (4.8%)
\$20,000 - \$34,999	2 (9.5%)
\$35,000 - \$49,999	3 (14.3%)
\$50,000 - \$74,999	3 (14.3%)
\$75,000 - \$99,000	5 (23.8%)
\$100,000 or greater	7 (33.3%)
Educational Attainment	
Some college, no degree	3 (13.6%)
Associate degree	4 (18.2%)
Bachelor's degree	8 (36.4%)
Graduate or professional degree	7 (31.8%)
Community Setting	
Rural	2 (9.1%)
Suburban	11 (50.0%)
Urban	9 (40.9%)
Relationship to Care Recipient	
Wife	11 (50%)
Husband	3 (13.6%)
Daughter	5 (22.7%)
Daughter-in-law	3 (13.6%)
Average Length of Time Caregiving (Range)	5.45 Yrs (.5 yrs – 18yrs)
Living Situation	
Lives with care recipient	18 (77.3%)
Does not live with care recipient	3 (22.7%)
Self-rated computer skills	(N = 21)
Beginner	1 (4.7%)
Average	12 (57.1%)
Advanced	7 (33.3%)
Expert	1 (4.7%)

Caregivers who enrolled in the study tended to report mental health challenges at the beginning of the study. Among the 21 caregivers who completed the PhQ-4 when they enrolled most reported experiencing mild (N = 10, 47.5%), moderate (N = 2, 9.5%) or severe (N = 2, 9.5%) depression, where 7(33.3%) scored in the normal range. All caregivers reported experiencing

some level of burden. Two (9.6%) scored in the mild range, 5 (23.9%) scored in the moderate range, and the remainder (N = 14, 66.5%) reported that they were experiencing high levels of burden. For knowledge about ADRD, the average score for caregivers on the Alzheimer's Disease Knowledge Scale at baseline was 25.71 (SD = 2.31, range 21-28).

### Methods

This project was carried out in two phases. Phase one addressed Aim 1 for the project, where the research team collected data at both memory clinics to learn how a new IT can best fit within the clinical workflow. Phase 2 addressed the project's second aim and tested the impact of using *CareHeroes* for a year on multiple psychosocial outcomes.

It should be noted that while Phase 1 was completed before the COVID-19 pandemic, the pandemic occurred just before initiating Phase 2. This posed numerous challenges to carrying out the project, as both clinics were closed to research activities for extended periods of time and when research activities were able to resume, it was required that all research activities be conducted virtually. Most patients and caregivers also received clinic services through telehealth during the study. As a result, the research team had to reconfigure the design for Phase 2 so that recruitment, data collection, and data analysis could be completed remotely. The research team was successful at carrying out the project in a virtual format, though numerous challenges persisted, which are discussed in other sections of this report.

#### Phase 1: Clinical Workflow Integration

To address Aim 1, the research team conducted a focus group with providers at each of the clinics (two focus groups total). The focus group guide was designed and structured to address the research question: *What are providers' (physicians, nurses, other staff) perceptions of how caregivers' use of CareHeroes influenced clinical workflow and care-related decision making for their patients?*

**Recruitment.** Each clinic was involved with conducting research studies and therefore all the clinic staff have some portion of their work effort to research activities. Both clinics agreed that participation in this project would count toward that effort and that there was no penalty for refusing to enroll in the study. The director of each arranged for the focus groups to take place during regularly scheduled clinic staff meetings to minimize workflow disruptions. At the beginning of each meeting, the participants were explained the purpose of the study and given a consent form to review and sign.

**Data Collection.** The UAB focus group was facilitated by Dr. Ruggiano and the MJH focus group was facilitated by both Drs. Ruggiano and Brown. Each lasted about one hour and were digitally recorded. At the beginning of each focus group, Dr. Ruggiano would give a presentation about the *CareHeroes* app and asked the participants for general feedback about its design and features. Then, a semi-structured focus group guide was used to steer the conversation and was broken down into three sections.

Section 1 included questions about current clinical workflow as it pertains to information sharing. Examples of questions included, *Who is the first person that the caregiver talks to about the patient's symptoms?; What happens to the information provided to that person?; Between the first person and the physician/nurse practitioner, is there someone else who receives information from the caregiver? (If yes) What is that process like?; When information about a*

patient comes from another health care setting, to what extent is that process similar or different?

Section 2 of the guide focused more specifically on *CareHeroes* integration, with questions such as: *If we have caregivers use the CareHeroes app, who would be the point (or best) person to receive the information from the app that is sent by the caregivers?; What would be the best next steps for that person to do with the information?*

Section 3 focused on general communication with caregivers, such as: *What has been the most challenging part of getting needed information from the caregivers so far?; What makes information sharing with caregivers easier?*

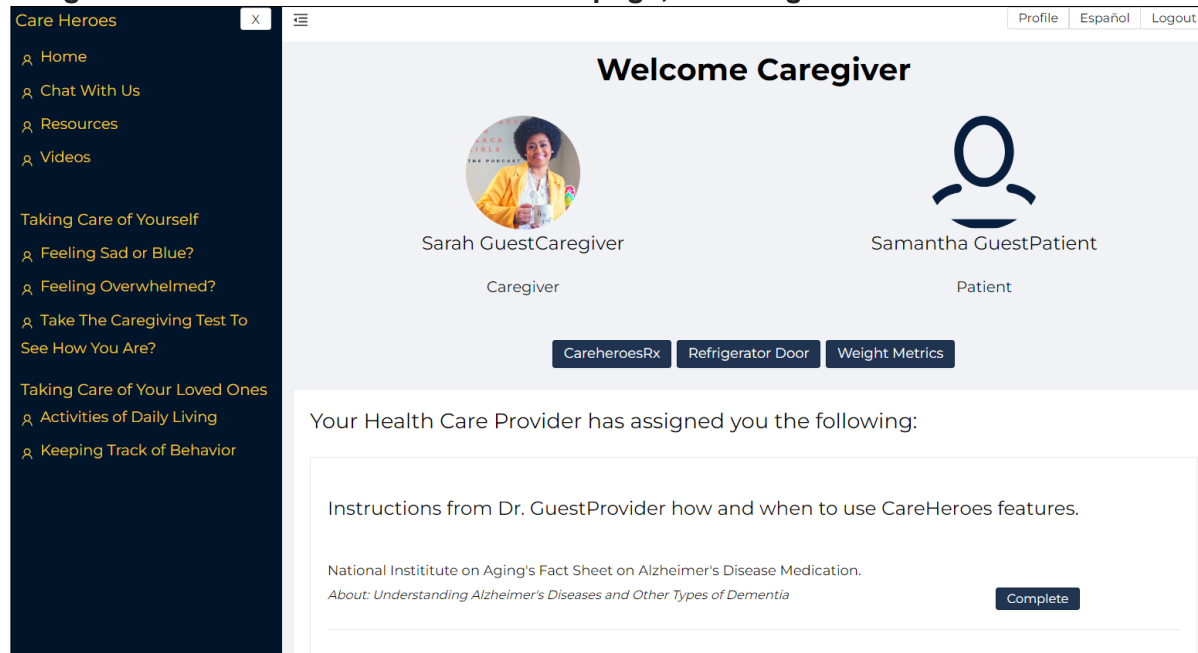
**Data Analysis.** The digital recordings from the focus groups were transcribed and reviewed for accuracy. Then, multiple research team members were involved with conducting a multi-step coding process to identify themes in the focus group data. The research team then mapped out a clinical workflow diagram for each clinic on how *CareHeroes* should be integrated into regular clinic activities (e.g., who is assigned to check *CareHeroes* for information from caregivers, how the information from caregivers on *CareHeroes* get included into the patient file.)

## Phase 2: *CareHeroes* Evaluation

Data from Phase 1 were used to make final revisions to the *CareHeroes* software before it was integrated into each clinic. The research team worked with the IT security departments at each clinic to make sure that the app was HIPAA compliant, and that data transferred through the app would be secure.

***CareHeroes* Intervention.** *CareHeroes* is a multi-functioning web-app that can be accessed via computer or the web browser on a smartphone. Image 1 shows a screenshot of the home page for the app, with icons for the different functions and features it offers.

**Image 1. Screenshot of *CareHeroes* homepage, featuring links to resources and features.**



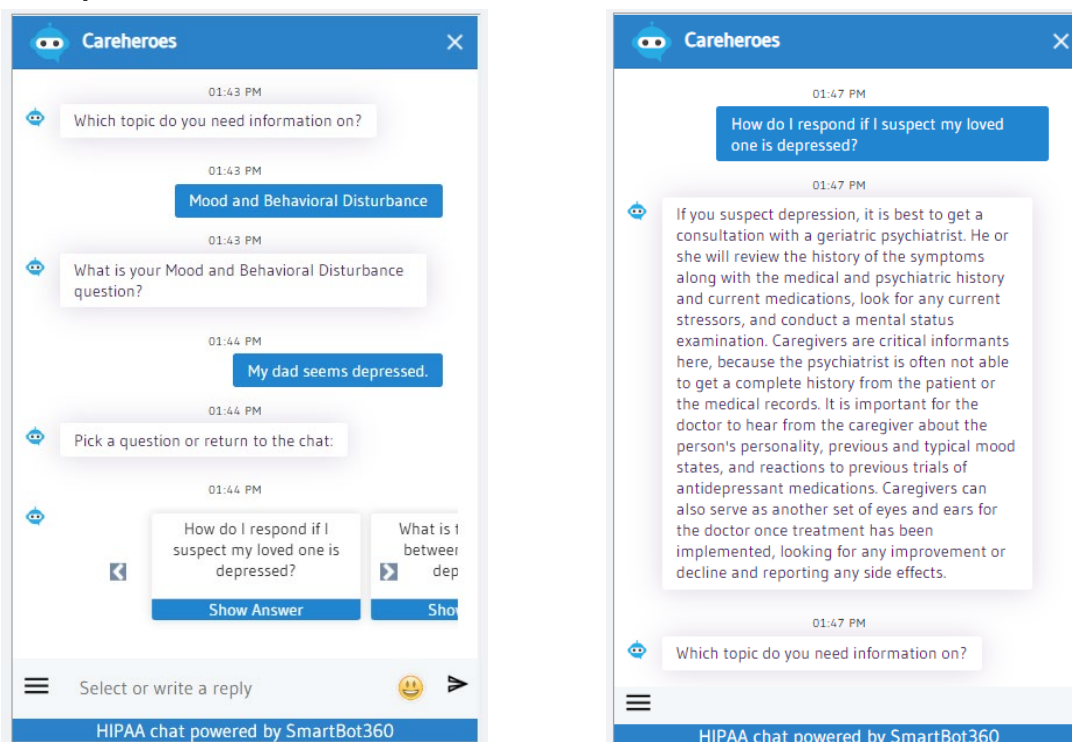


**Caregiver Education.** One of the several features offered by *CareHeroes* is caregiver education. Under the tab *Resources*, users will find a set of links to vetted content available on the web available through organizations, such as AARP, the Alzheimer’s Association, and the National Institute on Aging. The resource links are divided into three categories: (1) Tips for Caregiver Self-Care, (2) Tips on Understanding Alzheimer’s Disease or Other Types of Dementia, and (3) Tips on Legal or Financial Issues.

There is also a link for educational videos. These videos have been developed by the research team and feature vignettes about common issues experienced by caregivers using scripts that are evidence-based. The two videos are *Preparing for a Medical Visit for Someone with Dementia* and *Caring for the Caregiver*. Both videos are available in English and Spanish.

The third educational feature is an educational chatbot which is designed to interact with the caregiver and respond to common questions that caregivers ask. The algorithm recognizes language in the caregiver’s question and bases its response on content from Dr. Marc Agronin’s book, *The Dementia Caregiver: A Guide to Caring for Someone with Alzheimer’s Disease and Other Neurocognitive Disorders*.<sup>39</sup> The chatbot is designed to recognize freeform language entered by the caregiver and offers topics and questions that the caregiver can explore (see image 2).

**Image 2. Screenshots of chatbot dialogue based on a caregiving asking about their father’s depression.**



**Caregiver Support.** *CareHeroes* also offers support for caregivers. One supportive feature is a series of self-assessments that caregivers can take, including: (1) the PhQ-2<sup>27</sup> for depression, (2) the Zarit Caregiver Burden Inventory<sup>28</sup>, and (3) the Positive Aspects of Caregiving Scale<sup>29</sup>. The software algorithm is designed to give the caregiver feedback based on their responses to

the assessment items. Image 3 has an example of the feedback and tracked data that the caregiver can access after completing the PhQ-2 where the results detected depression.

**Image 3. Screenshots of the feedback from the PhQ-4 results (top) and chart of tracked data for caregiver depression (bottom).**

The test indicates you are experiencing depression symptoms.

What should you do?

Please contact your health care provider as soon as possible.

Click on the button to go back to your home page.

[Home](#)

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Previous Submissions

The following table displays the data of your previous submissions. At most three surveys will be displayed. If there exist more, use the arrows to navigate through them.

Question(s)	05-12-2022	05-17-2022	12-06-2022
1. Little interest or pleasure in doing things.	More than half the days	More than half the days	Nearly every day
2. Feeling down, depressed, or hopeless.	Several days	Several days	More than half the days

Another supportive feature includes validated clinical assessments that the caregiver can take based on their observations of the PLwD. The caregiver can complete the assessments in real time and at any location, including: 1) the Revised Memory and Behavior Problem Checklist<sup>30</sup>, and 2) Activities of Daily Living<sup>31</sup>, and 3) care recipient’s weight. The app’s algorithm is designed to track assessment results over time and can also be shared with the provider of the care recipient. Image 4 shows an example of the RMBPC and its resulting table with tracked data. Unlike the caregiver self-assessments, the memory clinic provider can log-onto *CareHeroes* and view the outcome reports from these self-assessments.

**Recruitment.** Caregivers were primarily recruited during telehealth visits with providers at the clinics. When the provider had a telehealth visit with a caregiver (typically over Zoom) they would tell them about the *CareHeroes* app and that they may benefit from participating in the study. The clinics also recruited caregivers from existing research participant pools and virtual caregiver support groups that they were offering during the pandemic. For caregivers who indicated interest in learning more about the study, the provider would give their name to a designated clinical team member who would coordinate with the research team to contact the caregiver, explain the goals and design of the study, and send the caregiver an electronic consent form to sign through either Docusign or the Qualtrics signature feature. Those who provided consent would have an interview session scheduled with a member of the research team at a date and time that was convenient for them. All recruitment materials were translated into Spanish by a professional translator.

**Image 4. Screenshots of questions from the Revised Memory and Behavioral Checklist (top) and tracked result data in a color-coded chart (bottom).**

Profile Español Logout

0%

### Instructions

For each symptom below, indicate if it has or has not occurred. If you select 'Yes' to any symptom, also select your reaction to that symptom from the drop down options

1. Asking the same question over and over.

No  
 Yes

Select Your Reaction

Select Reaction ▾

2. Trouble remembering recent events.

No  
 Yes

Select Your Reaction

Select Reaction ▾

3. Trouble remembering significant past events.

No  
 Yes

Select Your Reaction

**Previous Submissions**

The following table displays the data of your previous submissions. At most three surveys will be displayed. If there exist more, use the arrows to navigate through them.

Question(s)	03-08-2021	07-23-2021	08-05-2021
1. Trouble remembering significant past events.	No Symptom	Very Much	Very Much
2. Trouble remembering recent events.	No Symptom	A Little	No Symptom
3. Asking the same question over and over.	No Symptom	No Symptom	No Symptom
4. Forgetting what day it is.	No Symptom	No Symptom	A Little
5. Losing or misplacing things.	Moderately	No Symptom	No Symptom
6. Starting but not finishing things.	No Symptom	No Symptom	No Symptom
7. Doing things that embarrass you.	No Symptom	No Symptom	No Symptom
8. Waking you and other members up at night.	No Symptom	A Little	No Symptom
9. Engaging in behavior that is potentially harmful to self and others.	No Symptom	No Symptom	No Symptom

**Data Collection.** Caregivers engaged in data collection interviews at baseline and 3-month, 6-month, and 12-month follow-up points. Each interview was conducted over the telephone or Zoom and lasted between 45 minutes and an hour. During the interview, the researcher would

record the participant’s responses using a Qualtrics survey link, which directly entered the responses in the project database.

**Caregiver Interview Data.** Caregivers were interviewed at baseline, 3-month, 6-month, and 12-month follow-up. Interviews lasted between 45-60 minutes and they could choose to have their interview conducted in English or Spanish. Table 2 lists the variables and measurement tools that were administered in the interviews. Measures were chosen for their psychometric properties as well as their availability in Spanish language. To minimize burden on caregivers, some assessments were administered at each timepoint, while others were administered at baseline and at 12-month follow-up.

**Table 2. List of variables and measures for caregiver interviews**

Variable	Measurement	Timepoint
Health Self-Management	Communication with Physician Scale <sup>32</sup>	Baseline, 3M,6M,12M
Satisfaction with Telehealth	Satisfaction with Telehealth Scale <sup>33</sup>	Baseline, 3M,6M,12M
Caregiver Self-Efficacy	The Revised Scale for Caregiving Self-Efficacy <sup>34</sup>	Baseline, 3M,6M,12M
Caregiver knowledge of ADRD	Alzheimer’s Disease Knowledge Scale <sup>35</sup>	Baseline 12M
Depression	PHQ-4 <sup>36</sup>	Baseline, 3M,6M,12M
Burden	Zarit Burden Interview <sup>28</sup>	Baseline, 3M,6M,12M
Satisfaction with <i>CareHeroes</i>		12M
Demographics		Baseline

In addition to caregiver interviews, usage data were collected directly from the *CareHeroes* software, which automatically deidentified the data before the research team accessed it. User data included the date and time that users made specific actions with the app (e.g., clicking links, entering reminder notes). The data collected through this means included:

- Dates and times for Log-in and log-out
- Dates and times for clicks on links for educational resources and videos
- Outcome scores for the care recipient clinical assessments (Revised Memory and Behavior Problem Checklist, Activities of Daily Living)
- Outcome scores for caregiver self-assessments (Zarit Caregiver Burden Inventory, PhQ-2, and Positive Aspects of Caregiving)
- Date and time when a caregiver entered a reminder

**Data Analysis.** Data recorded through Qualtrics and *CareHeroes* were entered into an SPSS database where they underwent several analyses, including descriptive statistics and paired-sample t-tests.

### Limitations

Like many research studies during this period, this study experienced numerous limitations as a result of disruptions due to the COVID-19 pandemic. Most notably, the two clinic sites for the study had restrictions for in-person research activities and so the project was mostly carried out virtually. Hence, there lacked opportunities to demonstrate the *CareHeroes* app for participants and training them how to use the app had to be conducted over the phone. Also, the healthcare clinics were both understaffed during the pandemic and therefore patient care was often prioritized over research activities. Therefore, clinic staff involved with the study had less time

and resources to engage in recruitment activities. These issues, as well as personal challenges that caregivers faced during the pandemic, impacted the study in several ways:

- Recruitment for the study was low and took 14 months. To enroll as many caregivers as possible, the decision was made to extend the planned recruitment period. This required the team to reduce the intervention period to 6 months for caregivers recruited later in the study.
- The project had high attrition. Fewer caregivers were interviewed for follow-up interviews and there was not enough data to evaluate outcomes at 6 and 12 months. Given that some of the study variables were only planned to be administered at baseline and 12-month follow-up, we were unable to evaluate outcomes for those variables. Project team members reported that many caregivers did not respond to emails or text messages for follow-up interviews.
- Few providers logged onto the app. Given that much of their clinical work involved various telehealth technologies, it was challenging to integrate a new telehealth app into their regular routine.
- In terms of measurement, the initial design for the study included measures for caregiver perceptions of family-centered care and care coordination. However, these measures included many items that referred to the caregiver's last visit to the clinic with the care recipient and since in-person contact was not taking place the team opted to include a measure for satisfaction with telehealth. This also resulted in limitations since many federal restrictions regarding telehealth were temporarily lifted and so the modalities used for telehealth were very different across caregivers, making some of the items on the measure irrelevant.
- Given that data were collected by multiple team members remotely, the strict reliance on telecommunications for data collection sometimes posed challenges. For example, losing power or internet connection during a data collection interview or problems with the Qualtrics settings resulted in inconsistent recording of data at times.

Anecdotally, many caregivers approached for recruitment reported to the clinic staff that due to their increased reliance on IT for telehealth (as well as other activities of daily life), they felt overwhelmed to learn a new technology or to transfer additional daily activities to a virtual format. Similarly, disruptions to work and home life for most of the clinic staff also made using *CareHeroes* a low priority for them. The clinics were understaffed, and increased usage of telehealth made it challenging for them to incorporate *CareHeroes* usage into their daily routine.

Despite these limitations, the research team was successful at completing the study and generating pilot data that may be used to inform subsequent research projects.

## Results

### Principal Findings: Clinical Workflow

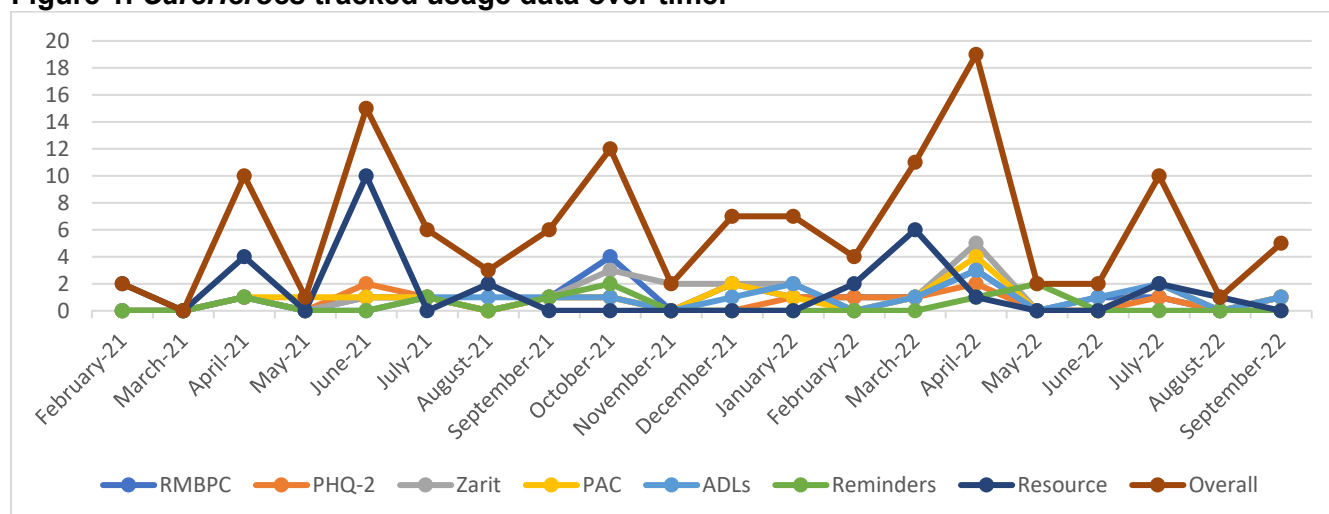
The focus groups in Phase 1 revealed that each clinic wanted different approaches to integrating *CareHeroes* into clinical workflow. For example, at the UAB site, the clinic staff preferred to have a nurse print out the data that caregivers entered into the app and make the printouts available to the provider on the day they were scheduled to return to the clinic. At the MJH site, the clinic staff preferred to scan caregiver data when it was received and enter it into the care recipient's patient file so that it was available to review in their file at any time before the upcoming visit. MJH staff preferred having a feature on *CareHeroes* that would notify staff when new information was entered by a caregiver. However, staff at UAB preferred not to have such a feature in fear of having notifications from patients and caregivers arrive from multiple

sources (e.g., voicemail, patient portal, email). Focus group data from both sites also revealed that providers thought that having a platform where the caregiver could complete clinical assessments of the care recipient at home could improve communication about patient care and ultimately improve quality of care.

### Outcomes: CareHeroes Evaluation

**User Data.** Overall, the project collected participant usage data between February 2021 and September 2022. It should be noted that recruitment for the project took place over a 14-month period, so the number of caregivers enrolled in the study at any given time varied from N = 2 to N = 12. The period with the largest number of caregivers enrolled at the same time was between December 2011 and August 2022, which is reflected in the usage data. Figure 1 displays the usage of data over the intervention period. Throughout the study there were 169 overall actions that caregivers made on *CareHeroes* (e.g., link clicks), which peaked in April 2022. The features most accessed by participants included the chatbot (44 sessions) resource links (30 clicks), the Zarit Caregiver Burden Inventory (22 submissions), and the Revised Memory and Behavior Problem Checklist (19 submissions). The reminder feature (8 entries) and PHQ-2 assessment (13 submission) were accessed less.

**Figure 1. CareHeroes tracked usage data over time.**



For the chatbot data, caregivers accessed the chatbot 44 times over the course of the study, though only interacted with the chatbot 25 times. The most common topic that caregivers explored on the chatbot were how to manage depression of the care recipient (N = 5 total chats), sleep problems experienced by the care recipient (N = 4 total chats), and about living wills (N = 4 total chats).

Several caregivers who provided qualitative data at the 12-month follow-up reported that they didn't use *CareHeroes* much during their time in the study. One reported that they didn't use the app, but they would have liked to since the features sounded helpful. Those who reported using it expressed that the educational information on the app was the most helpful to them. One caregiver reported that the chatbot was the most helpful feature on the app because they were able to ask questions virtually and receive prompt responses. Caregivers who reported they did not use *CareHeroes* very much did not provide reasons that they did not use it. It is possible that an in-person training or tutorial videos in the future could promote greater use of the app.

Caregiver Outcomes. Overall, 21 caregivers were interviewed at baseline and among those, 13 were interviewed at the 3-month follow-up. The research team examined differences in the outcome variables based on caregiver characteristics at baseline and 3-month follow-up. At baseline, it was found there were a significant association in depression and caregiver burden based on income (see tables 3 and 4), though these differences disappeared at 3-months.

**Table 3. Bivariate analyses for Zarit score outcome by time period**

	Baseline			3-Month		
	M (SD)	T/F	p-value	M (SD)	T/F	p-value
Caregiver Sex						
Female	21.22 (8.14)			--		
Male	14.67 (10.07)	-1.26	0.22	--		
Caregiver Race						
White/Caucasian	19.78 (8.73)			20.60 (8.58)	-	
African American/Afro-Caribbean	23.33 (7.51)	-0.66	0.52	26.33 (2.08)	1.12	0.29
Hispanic Origin						
Not Hispanic	21.26 (6.22)			--		
Hispanic	23.33 (14.83)	0.09	0.93	--		
Relationship						
Wife	20.00 (8.00)			26.00 (6.00)		
Husband	15.00 (10.00)			18.00 (8.00)		
Daughter-in-law	31.00 (7.00)	2.27	0.08	28.00 (0.00)	2.54	0.12
Daughter	18.00 (5.00)			16.00 (8.00)		
Income						
Less than \$20,000	37.00 (0)			--		
\$20,000 to \$34,999 <sup>a</sup>	5 (1)			--		
\$35,000 to \$49,999	22 (4)			24.00 (1.00)		
\$50,000 to \$74, 999 <sup>a</sup>	29 (4)	8.42	<0.001	28.00 (1.00)	1.66	0.25
\$75,000 to \$99,999 <sup>b</sup>	17 (3)			16.00 (8.00)		
\$100,000 or more <sup>a</sup>	20 (6)			22.00 (9.00)		
Education						
Some college, no degree	14.00 (5.00)			14.00 (0.00)		
Associated degree	22.00 (9.00)			22.00 (9.00)		
Bachelor's degree	21.00 (11.00)	0.56	0.65	21.00 (10.00)	0.45	0.72
Graduate or Professional degree	21.00 (7.00)			24.00 (7.00)		
	Pearson's r		p-value	Pearson's r		p-value
Caregiver Age		0.07	0.77		0.39	0.19
N		21			13	

<sup>a</sup>. Baseline post-hoc statistically significantly different from \$20,000 to \$34,999

<sup>b</sup>. Baseline post-hoc statistically significantly different from Less than \$20,000

(--) Denotes zero observations for that category

**Table 4. Bivariate analyses for PhQ4 score outcome by time period**

	Baseline			3-Month		
	M (SD)	T/F	p-value	M (SD)	T/F	p-value
Caregiver Sex						
Female	3.00 (1.00)	-0.69	0.50	3.10 (1.79)	-1.25	0.24
Male	4.11 (2.72)			1.67 (1.53)		
Caregiver Race						
White/Caucasian	4.17 (2.62)	0.94	0.36	3.10 (1.91)	1.25	0.24
African American/Afro-Caribbean	2.67 (2.08)			1.67(0.58)		
Hispanic Origin						
Not Hispanic	3.56 (3.63)	1.03	0.22	--		
Hispanic	5.20 (2.13)			--		
Relationship						
Wife	5.00 (3.00)	1.32	0.30	4.00 (2.00)	1.72	0.23
Husband	3.00 (1.00)			2.00 (1.00)		
Daughter-in-law	5.00 (4.00)			2.00 (0.00)		
Daughter	2.00 (1.00)			2.00 (1.00)		
Income						
Less than \$20,000	9.00 (0.00)	3.17	0.04 <sup>a</sup>	--	1.72	0.24
\$20,000 to \$34,999	2.00 (1.00)			--		
\$35,000 to \$49,999	2.00 (1.00)			2.00 (1.00)		
\$50,000 to \$74, 999	5.00 (4.00)			4.00 (2.00)		
\$75,000 to \$99,999	2.00 (1.00)			2.00 (1.00)		
\$100,000 or more	5.00 (2.00)			3.00 (1.00)		
Education						
Some college, no degree	4.00 (4.00)	0.16	0.92	2.00 (0.00)	0.15	0.93
Associated degree	5.00 (4.00)			3.00 (2.00)		
Bachelor's degree	4.00 (3.00)			2.00 (2.00)		
Graduate or Professional degree	3.00 (2.00)			3.00 (2.00)		
	Pearson's r		p-value	Pearson's r		p-value
Caregiver Age	0.06		0.78	0.46		0.11
N			21			13

<sup>a</sup> Significant F ratio, however, post-hoc analyses showed no significant differences between the categories.

A paired-sample t-test was performed that compared the outcome variables between baseline and 3-months for the 13 caregivers who completed both interviews (see table 5). It was found that caregiver burden was about the same at baseline (M = 21.85, SD = 6.38) and at the 3-month follow-up (M = 21.92, SD = 7.89),  $t(12) = -.07$ ,  $p = 0.95$ . Caregivers scored higher on the PhQ-4 for depression at baseline (M = 3.69, SD = 2.46), compared to the 3-month follow-up (M = 2.77, SD = 1.79), though this difference was not statistically significant,  $t(12) = 1.56$ ,  $p = 0.15$ . There was not enough data at follow-up to assess caregiver self-efficacy or perceptions of shared decision making.



	M (SD)	T	p-value
Zarit			
Baseline	21.85 (6.38)	-0.07	0.95
3-month	21.92 (7.89)		
PhQ-4			
Baseline	3.69 (2.46)	1.56	0.15
3-month	2.77 (1.79)		
N		13	

### **Discussion and Implications**

Overall, this study found that caregivers used the *CareHeroes* app for several caregiving purposes, including looking for information about dementia and caregiving, tracking clinical assessments of the care recipient’s behavior, and completing self-assessments for their own mental health. The study also found that caregivers were willing to use a chatbot to learn more about dementia and caregiving. The study did not find that using *CareHeroes* had an impact on caregiver mental health outcomes, such as depression and burden. The data did not allow for an assessment for changes in caregiver self-efficacy, knowledge about dementia, or perceptions to shared decision making about health.

Initially, the research team thought that the COVID-19 pandemic provided an opportunity for offering caregivers a new telehealth technology designed to support and educate caregivers of PLWD. However, it was found that the increased reliance on telecommunication technologies and disruptions to the healthcare clinics posed significant challenges to integrating a new IT into a clinical setting with this population and within this clinic setting. Both the clinic staff and the caregivers reported experiencing significant stress and burden during the pandemic and that as a result, learning a new software program was overwhelming. It is not clear how *CareHeroes* usage may have differed under non-pandemic circumstances. Also, the disruption caused by the pandemic on every-day living resulted in increased stress, depression, and burden for the general population. It is not clear the extent to which mental health challenges caused by the pandemic in general may have influenced caregiver depression and burden.

In conclusion, more research is needed to better understand how *CareHeroes* may impact caregiver and clinical outcomes. It is possible that outcomes of future studies may yield different results when caregivers and providers are not facing extremely stressful challenges that are unrelated to dementia care or caregiving, like the pandemic. However, one of the more significant implications of this study is that new health IT needs to be better integrated into the daily activities for caregivers and clinicians for them to adopt them as part of daily care. For example, if *CareHeroes* had functions that supported daily caregiving tasks, caregivers would remember to use the app more often and therefore access more of its clinical tracking features.

From the clinicians’ perspective this is also true, but there is a need for new technologies to be integrated better with existing IT systems that clinicians are using. One clinic staff member reported that one of the barriers to using *CareHeroes* was that it required a log-in. He stated that many activities required for clinical care are housed on their own platforms and each requires a separate log-in. Hence, it is not enough for new IT to be useful and innovative, tech development needs to focus more on interoperability and integration with existing technologies

that clinicians use for regular patient care. For example, many of the patient assessments that *CareHeroes* tracks (e.g., patient depression, symptomology) are not traditionally collected through patient portals. However, patient portals are already an established IT used regularly in patient care. Hence, rather than introduce another platform for patient care that is in addition to other health IT being used as part of clinical workflow, finding ways to integrate new IT into existing patient portals may make them easier to adopt.

## Conclusion

While disruptions due to the COVID-19 pandemic created significant challenges to carrying out this study, the study was successful at learning more about how IT may be used by caregivers to support their caregiving. While the outcome data did not show that *CareHeroes* had an impact on mental health or other psychosocial variables for caregivers, the usage data provides some insight on what features caregivers may find most helpful and therefore more likely to adopt. Given that health care facilities continue to be understaffed and many caregivers are opting to continue telehealth at both clinics (rather than in-person visits), future research may examine the feasibility and efficacy of using a multi-functional app, such as *CareHeroes*, to empower caregivers in community-based settings as they navigate complex health and long-term care systems.

## List of Publications and Products

1. CareHeroes (version 2.0) [Computer Software].
2. Ruggiano N., Brown EL, Framil CV, Hurley S, Roberts L, Clarke P, Allala, S C, & Daquin J. (2022, November). Supporting Dementia Caregivers During COVID-19 with CareHeroes IT: Usage Patterns and Outcomes. Poster presented at: Annual Scientific Meeting of the Gerontological Society of America; November 2-6, 2022; Indianapolis, IN.
3. Ruggiano N, Brown EL, Clarke P. Integrating Health IT into Clinical Workflow for Dementia Care: Provider and Caregiver Perspectives. Poster presentation given at the Annual Scientific Meeting of the Gerontological Society of America November 13-17, 2019; Austin, TX.

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