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CareHeroes Web and Android™ Apps for Dementia Caregivers:

A Feasibility Study

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Abstract

The purpose of the current feasibility study was to examine the use, utility, and areas for refinement of a newly developed web-based and Android™ application (app) (i.e., CareHeroes) with multiple features to support individuals caring for loved ones with Alzheimer's disease or other forms of dementia (AD). The study was performed over an 11-week period with triads of AD caregivers, assigned home care case managers, and primary care providers (PCP). The study involved quantitative and qualitative methodologies. Eleven AD caregivers (seven daughters, two sons, and two spouses), six case managers, and five PCPs participated. Data demonstrate participants were mostly satisfied with the multiple features and ability to access and use CareHeroes. Barriers for use include concerns about time constraints and not being familiar with technology. Although the study findings are promising, a longer term study to evaluate the impact of the CareHeroes app is indicated.

More than 5.4 million individuals in the United States are affected by Alzheimer's disease and other forms of dementia (AD). AD is a leading cause of disability worldwide and disproportionately affects African American individuals and individuals of Hispanic descent (Alzheimer's Association, 2014). Most individuals living with AD reside in the community, receive care and support from family/informal caregivers, and are medically managed by their primary care provider (PCP). In 2012, the physical and emotional impact on AD caregivers was estimated to have resulted in \$9.3 billion in health care costs in the United States (Alzheimer's Association, 2014). Although AD caregivers often report satisfaction

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with the ability to provide care, it is well documented that AD caregivers often have psychiatric and physical consequences associated with caregiving (Brodaty & Donkin, 2009; Clyburn, Stones, Hadjistavropoulos, & Tuokko, 2000; Gonyea, O'Connor, Carruth, & Boyle, 2005; National Hispanic Council on Aging, 2013; Williams, 2005; Zarit, Reever, & Bach-Peterson, 1980).

Sources of caregiver stress and burden include lack of a support network, insufficient or overwhelmed coping skills, low use of formal and informal services, and care recipient problem behaviors (Alzheimer's Association, 2014; Hillestad et al., 2005; James et al., 2014). Several efficacious caregiver interventions (i.e., in-person, telephone, psychoeducation, and emotional support) have been developed to educate and support AD caregivers, but these interventions have not been widely disseminated and remain mostly inaccessible (Gitlin, Marx, Stanley, & Hodgson, 2015). There have been recent attempts to address this problem. Most studied caregiver interventions were designed to be delivered by a specialized trained clinician, in a multiple session format, and are administered in-person, on a one-on-one basis or in small groups.

Health Information Technology (HIT) has been identified as a promising way of addressing compromised health care for patients with AD (Aminzadeh, Molnar, Dalziel, & Ayotte, 2012) and issues experienced by caregivers (Czaja & Rubert, 2002). Once developed, web- and smartphone-based support resources are inexpensive to implement and, therefore, offer great potential. The Center for Technology and Aging (CTA; 2014) concluded, "New technologies (also) can make family caregivers' lives easier by giving them tools to more easily support their loved ones being able to age in place" (p. 2). Three recent systematic reviews (Boots, de Vugt, van Knippenberg, Kempen, & Verhey, 2013; Godwin, Mills, Anderson, & Kunik, 2013; McKechnie, Barker, & Stott, 2014) and a literature review (Topo, 2009) critically evaluated and summarized evidence on HIT (i.e., Internet, computer, and technology) interventions targeting dementia caregivers. The three systematic reviews included a total of 34 studies (11 were included in two or more reviews). Although studies report positive outcomes (e.g., decreased caregiver depression, increased self-efficacy for caregiving), the variation in the HIT intervention features, differing outcome measures, lack of control groups, short follow-up periods, and few randomized trials does not allow for a firm conclusion regarding their benefits for caregivers (Boots et al., 2013; Godwin et al., 2013; McKechnie et al., 2014). The authors of the three systematic reviews concluded more randomized trials and high-quality research are needed to evaluate the impact of these HIT caregiver intervention studies.

The U.S. Department of Health and Human Services (2007) has specifically identified the need for developing HIT for the home care setting to improve the exchange of patient information. For instance, given the communication and memory problems associated with AD, PCPs often have difficulty collecting health information needed for clinical decision making (Hinton et al., 2007). In addition, the need for one or more caregivers to convey necessary patient information during the medical encounter often results in office visits that are more time consuming than what is typically allotted for patients (Hinton et al., 2007).

Many home care agencies currently collect and maintain patient records electronically, although the majority use electronic patient records for basic functions, such as maintaining patient demographics and reimbursement (Hunt, 2008). However, few use HIT for the purpose of coordinating care or sharing and involving patients and caregivers in care planning (Bates & Bitton, 2010). Given that AD caregivers and home care case managers have access to psychosocial data that are not traditionally captured through existing HIT used by physicians, using HIT to link these individuals with health care providers would increase the meaningful use of HIT and potentially improve clinical decision making and care coordination for patients with AD (Glasgow, Kaplan, Ockene, Fisher, & Emmons, 2012). Unfortunately, there are significant barriers to linking providers across institutional settings easily and securely with current technologies (Ruggiano et al., 2012).

The current authors' multidisciplinary research team (i.e., nurse, social worker, physical therapist, computer engineer, and health economist), in partnership with local service providers, developed the CareHeroes (access <http://v75.cs.ucr.edu/careheroes-demo/home/about>) web-based and Android™ applications (apps) designed to support AD caregivers and facilitate communication and the effective exchange of information between AD caregivers and health care providers across health care settings (i.e., home care and primary care) (Page, Brown, Ruggiano, Roberts, & Hristidis, 2012). The purpose of the current feasibility study is to examine the use and perceived utility for dementia care, and to identify opportunities for improvement of CareHeroes. Prior research on HIT interventions has not linked these three groups of stakeholders for the purpose of addressing the needs of patients with AD and their caregivers.

STUDY AIMS

The aim of the current feasibility study was to evaluate the implementation of CareHeroes among triads of AD caregivers, home care case managers, and PCPs. Consistent with the purpose of a feasibility study for a new intervention, the use and perceived utility were assessed, and opportunities for revision and improvement were identified (Polit & Beck, 2012) when implemented in a cross-institutional setting (primary care and home care). To address this aim, the following questions were posed:

1. How often and for what purpose do family caregivers, case managers, and PCPs access CareHeroes?
2. How do users (i.e., family caregivers, case managers, and PCPs) view the utility of CareHeroes in providing AD care?
3. In what ways do users think the design of the CareHeroes app could be improved to facilitate meaningful use, and what are the constraints (i.e., obstacles) for use in AD care?

METHOD

The current feasibility study was conducted in collaboration with United HomeCare, a large, nonprofit home health care agency located in Florida, using a quasiexperimental design with triads (i.e., AD caregivers, case managers, PCPs) and multiple data collection methods.

Triangulation provided the opportunity to capture the opinions and perspective from a variety of target populations that would use CareHeroes. Data were collected over an 11-week period. The study procedures were approved by the Florida International University Institutional Review Board.

Intervention

Caregivers, case managers, and PCPs were asked to: (a) participate in a brief (10 to 30 minutes) initial orientation session with a research team member where features of CareHeroes were demonstrated; (b) use CareHeroes over the 11-week study period as part of their routine care activities and review information provided by other CareHeroes users; and (c) provide their input at the end of the study period about their experiences using CareHeroes. During the 11-week study, the research team sent weekly text reminders for caregivers to update and review information on CareHeroes and complete assessments as needed. These messages included inspirational sayings, information, and a link to CareHeroes.

The CareHeroes (web-based and Android smartphone) app interface and content were developed with a user-centered design and input from potential users of CareHeroes (e.g., case managers, family caregivers, PCPs) in an effort to increase adoption of the technology. In addition, family-centered theory was used as a theoretical framework in developing CareHeroes. *Family-centered theory* posits that the health care system must engage family systems for the purpose of promoting quality of life and health in chronic care (Bamm & Rosenbaum, 2008). Family members are viewed as having expertise in the needs of an individual with a chronic condition and therefore should be viewed as partners with providers in providing care and health decision making. Aligned with these principles, CareHeroes was designed to provide caregivers with a platform for bidirectional sharing of observations and knowledge with providers about care recipients and, therefore, provide them with information and support for caregiving activities.

Decisions about content to be included were based on the team's experience, existing scholarship, pilot work, and professional group recommendations (Alzheimer's Disease Caregiving Advisory Group, 2009; Kelly, 2015). The finalized content was organized into four domains: (a) information, (b) linkages to services, (c) emotional support (i.e., Caregivers Corner), and (d) decision support. Collectively, the content is consistent with the Alzheimer's Disease Caregiving Advisory Group (2009) recommendations, and multicomponent HIT interventions have been shown to be beneficial for caregivers (Boots et al., 2013). All content was viewable and printable by all users (i.e., caregivers, case managers, PCPs) except the Caregivers Corner, which is described below.

Information—Several types of information are available in the CareHeroes apps: (a) information from the care recipient's recent Florida Department of Elder Affairs 701-B Comprehensive Assessment, a biopsychosocial assessment (includes sociodemographic indicators, clinical information, pain, activities of daily living, instrumental activities of daily living) completed by a case manager; and (b) educational information and links to websites focused on AD caregiving and caregiver wellness. In addition, the caregiver alert

function notifies the case manager to call or e-mail the caregiver for non-urgent issues or questions (Figure 1 and Figure 2).

Linkages—CareHeroes includes organized vetted web links and contact information for local, state, and national caregiver resources and services.

Caregivers Corner—CareHeroes provides caregivers with the ability to assess their own symptoms of depression and burden with established reliable and valid measures at the Caregivers Corner. Caregiver depression was self-assessed by the caregiver using the 2-item Patient Health Questionnaire-2 (scale from 0 to 6, with a cutoff score of 3; higher score indicates depression), which provides a quick screen for depression (Kroenke, Spitzer, & Williams, 2003). Caregivers may also self-assess for burden symptoms using the 4-item Zarit Burden Scale (scale from 0 to 16; score 8 indicates significant burden), which is a quick assessment of their current feelings of stress or strain (Bédard et al., 2001). These instruments were chosen based on their brevity and established properties. If the caregiver responses indicated that he/she was experiencing a high level of depression or burden, a branching algorithm allowed for an automated prompt from CareHeroes and would recommend contacting the case manager and provided a list of resources for reducing depression and burden symptoms.

Decision Support for Caregiver Management—CareHeroes content also allows caregivers to maintain a list of care recipient medications and document memory and behavioral disturbance observations (weekly) to be shared with the PCP and case manager. The latter is assessed using the Revised Memory and Behavior Problems Checklist, a 24-item caregiver-reported measure of observable memory difficulties and behavior problems in patients along with a parallel assessment of the caregiver's reaction to these behavioral problems (Teri et al., 1992). The checklist is a reliable and valid assessment that asks the caregiver to rate the frequency of care recipient problems (0 = *never occurred* to 4 = *daily or more often*) within three subscales (i.e., memory-related, depression, and disruptive behaviors). The caregiver rates the frequency of each behavior problem during the past week and his/her reaction to the behavior (i.e., how bothered or upset the caregiver feels when the behavior occurs [0 = *not at all* to 4 = *extremely bothered*]).

Prior to conducting the current feasibility study, the authors performed usability tasks with potential users: caregivers, case managers, and PCPs. Users were provided with a brief introduction and were asked to navigate the site prompted with tasks (i.e., "Please show me how you would locate information about respite care"). Information from the usability tasking and general feedback from users regarding the appearance and display of information were used to refine the CareHeroes apps. To promote adoption, the user interface was designed for middle-aged and older adults using principles outlined from the National Institute on Aging and National Library of Medicine (2002). Design features included not using technical terms or jargon, adding directions, simple navigation features, minimized architecture, larger font, high-contrast colors, and minimized information.

Implementation of CareHeroes

CareHeroes provides a secure web-based platform that can be used by providers across institutions. To ensure and enhance data security, an IT security data expert and institutional Private Health Information Privacy Officer were consulted to ensure adherence to privacy standards. To ensure the security of the system, the team deployed a secure certificate (SSL) on both the web-based and Android apps, allowing HTTPS-encrypted communication between the client (i.e., browser or mobile phone) and the server, preventing any man-in-the-middle attack or spoofing. Further, CareHeroes required passwords to access any data, and passwords were stored in the database in an encrypted format. The team also forced browsers not to save any data or passwords to avoid caching-related security issues. AD care recipients' information was automatically uploaded by the community partner's secure server, where it was maintained for the duration of the study. No health information was transferred to an external server, nor was it collected by the research team for any research purposes.

Recruitment

The current feasibility study required recruitment of caregivers, the assigned case managers, and the client's PCP. The recruitment activities occurred in Miami, Florida. AD care recipients were not actively involved in this study. Caregivers were eligible to participate in the study if they: were the identified caregiver for a care recipient with AD who was receiving home and community-based services from United HomeCare; were legally able to have access to the care recipient's health information and make health-related decisions on his/her behalf; lived within a 30-minute drive from the care recipient; had Internet access through a computer or Android smartphone; and were able to speak and read English. Case managers were eligible for the study if they were assigned to the case of a consenting family caregiver. PCPs were eligible if they were the prescribing provider for the care recipient.

Case managers had an average of 80 clients and were asked to identify potentially eligible caregiver participants from their caseloads and determine if they were interested in learning about the study. Two members of the research team (L.R., K.L.W.) contacted those who were deemed eligible and interested in participation to describe the goals, risks, and procedures of the study, and to obtain consent using an online form. Approximately 25 caregivers were contacted and 14 AD caregivers were recruited and provided consent; however, two caregivers had their care recipient pass away and one withdrew for medical reasons, leaving 11 who completed the study. Once caregivers consented to participate in the study, the PCP listed in the care recipient's file was contacted by the research team for recruitment. Eleven PCPs were contacted to participate and five consented and enrolled in the study. One PCP declined to participate as he routinely did not use web-based information in providing health care, and another PCP was on extended leave. All six case managers enrolled in the study. PCPs and case managers were required to sign a consent form to participate. Caregivers were given a \$50 gift card for their participation and PCPs were given a \$75 gift card. Case managers were provided time release from their regular duties to participate in the study and were asked to use CareHeroes for their regular work activities and, therefore, were not provided additional compensation.

Data Sources

Following participant consent, a brief survey was conducted to collect baseline demographic data from all users. In addition, caregivers were queried about their computer skills and the average number of hours spent each week on the Internet. Multiple sources of data to assess the CareHeroes apps to address the research questions were collected following the 11-week study. The research team triangulated findings from the multiple data collection methods to evaluate the implementation of CareHeroes. A combination of tracking data, surveys (caregivers and PCPs), and a case manager focus group were used. Survey items were compiled into Qualtrics online survey software and e-mailed to participants using a link, and up to three reminders were sent.

Data on CareHeroes use were collected from all users with tracking data to assess case manager, PCP, and caregiver use of the CareHeroes features. The apps were designed to collect information in real-time about the frequency that specific features were used, the types of information accessed, and the purpose of notifications. Time stamps were recorded for each action that was taken. An *action* is defined as an operation that a user is performing on the website, either through clicking a button or by following a hyperlink. An action typically takes the user to a new web page.

Data on utility, experience with, and suggestions for improvement for CareHeroes were collected from caregivers and PCPs by administering a web-based survey following the 11-week study period. The surveys included multiple items to assess CareHeroes utility from existing measures of health care and HIT that were modified to reflect CareHeroes content. The caregiver survey used modified questions from the Agency for Healthcare Research and Quality's Health Information Technology Survey Compendium (access <http://www.healthit.ahrq.gov>) and the "Shared Care Plan Satisfaction Survey," developed by the PeaceHealth organization in Bellview, Washington (access <https://healthit.ahrq.gov/health-it-tools-and-resources/health-it-survey-compendium/shared-care-plan-satisfaction-survey>). The caregiver survey contained multiple items focused on the utility of CareHeroes, including: eight items on caregivers' level of agreement (response options: *disagree*, *somewhat disagree*, *somewhat agree*, *agree*, or *do not know*) of the extent to which CareHeroes helped with various aspects of caregiving; 10 items about their level of satisfaction (response options: *dissatisfied*, *somewhat dissatisfied*, *somewhat satisfied*, *satisfied*, or *do not know*) with CareHeroes functions; 10 items about how important (response options: *unimportant*, *somewhat unimportant*, *somewhat important*, *important*, or *do not know*) the functions of CareHeroes were to them; and five items regarding ease of navigation and task completion (response options: *disagree*, *somewhat disagree*, *somewhat agree*, *agree*, or *do not know*). In addition, the caregiver survey included open-ended questions regarding suggestions for improvement and obstacles for CareHeroes use in AD care.

The PCP survey included modified items from the "Provider Experiences With and Perceptions of Current Patients' Use of E-mail Communication With Their Doctor" survey, developed at the University of Missouri (Keplinger et al., 2013). The survey contained items to assess the purpose of the PCPs' use of CareHeroes as well as their perception of the utility of CareHeroes and its potential impact on patient outcomes and the efficiency of their practices. The only modification required in the survey was changing the name of the

technology to “CareHeroes.” The PCP survey included open-ended questions focused on suggestions for improvement and obstacles of CareHeroes in AD care.

A focus group was conducted with the case managers to collect data on the utility, experience with, and suggestions for improvement and obstacles of CareHeroes. A semi-structured focus group guide was used that contained questions about their actual experience with using CareHeroes, their observations of caregivers’ experiences with using CareHeroes, and potential improvements and obstacles for use in AD care. The decision to conduct focus groups with case managers to explore their reaction and recommendations to the CareHeroes apps was made for several reasons. The focus group format provides participants with the opportunity to consider and comment on other participants’ responses. Because this was an 11-week feasibility study, it was anticipated that use would vary by caregivers and the authors wanted case managers to hear about and be able to comment on interactions with CareHeroes based on their colleagues’ experiences. It was not practical to conduct focus groups with caregivers and PCPs due to logistics and time constraints of these users. The case manager focus group was approximately 90 minutes long, audiorecorded, and transcribed verbatim.

Data Analysis

For the tracking data, descriptive statistics were generated to determine overall use, frequency of use, and use of specific items and functions, such as the notification feature and educational materials, within the 11-week study period. Descriptive statistics of case manager and PCP survey data were computed using Stata version 13.

Focus group data were transcribed verbatim and underwent a systematic process of coding where codes were initially assigned freely to segments of text that represented the meaning of the text, codes that were related or similar were placed into categories, and codes and categories were compared and contrasted to identify larger themes. Two researchers (E.L.B., N.R.) were involved in assessing the codes and themes to ensure trustworthiness of data.

RESULTS

Sample Characteristics

Demographic characteristics of the 11 caregivers, six case managers, and five PCP participants are displayed in the Table. Caregiver demographics (i.e., relation to the care recipient and age) are consistent with national data (Alzheimer’s Association, 2014). Six caregivers reported they spend an average of 10 hours on the Internet per week, one caregiver reported spending 4 to 10 hours, and three caregivers reported spending 1 to 3 hours per week on the Internet. Caregivers were asked to rate their own computer skills (response options: *beginner* [$n = 2$], *average* [$n = 3$], *advanced* [$n = 4$], or *expert* [$n = 1$]). All six case managers had at least an undergraduate degree (social work or psychology) and two reported having a Master’s degree (social work or counseling). Of the PCPs, all of the MDs ($n = 4$) were Internists, one was a sub-specialist (pulmonary medicine), and the nurse practitioner was a certified Family Nurse Practitioner.

Research Question 1

Use of the CareHeroes app was tracked for the 11-week study period. Users logged in, on average, 2.18 times over the study period, for a total number of 349 actions. Use continued to increase over the study period (Figure 3). Three hundred (86%) actions occurred via the web-based app and 49 (14%) via the Android app. The most used feature was the caregiver assessment of the care recipient's memory and behavior using the Revised Memory and Behavior Problems Checklist (30 actions) and educational resources (28 actions). Of the 22 users (11 caregivers, six case managers, and five PCPs), 50% ($n = 11$) accessed and used the CareHeroes resources. Users included four case managers, five caregivers, and two PCPs. Of 349 actions, caregivers were responsible for the most use (85%, $n = 297$). All case managers and PCPs accessing CareHeroes reviewed care recipient-related health information. Use of CareHeroes varied: two users accessed CareHeroes more than two times, nine users accessed CareHeroes less often (i.e., one to two times), and there were 11 non-users (no use).

Research Question 2

Participants were queried about the utility of CareHeroes. Caregivers and PCPs were surveyed and case managers were invited to participate in a focus group. Ten of 11 caregivers completed the caregiver survey at the end of the 11-week study period. Regarding CareHeroes utility, six caregivers *agreed* or *somewhat agreed* that "CareHeroes helps with the ability to organize and keep track of my loved one's health care information (such as medications)." Five caregivers *agreed* or *somewhat agreed* that "CareHeroes helps me understand my choices and make better decisions about my loved one's health," and five caregivers *agreed* or *somewhat agreed* that "CareHeroes helps me feel more confident that I can figure out solutions when new situations or problems arise." Of the 10 caregivers who completed the survey, more than one half reported being *somewhat satisfied* or *satisfied* with six CareHeroes features, including the (a) alert function, (b) e-mail function, (c) Caregivers Corner (i.e., the ability to assess their own symptoms of depression and burden), (d) the capacity to keep track of the care recipient's mood and behavioral disturbances, (e) printer function (i.e., ease of printing materials from the CareHeroes website), and (f) the hyperlinks to caregiver information. Caregivers rated the following features as being the most important ones available through CareHeroes: Caregivers Corner ($n = 7$); alert function ($n = 7$); assessment of behavioral and mood disturbances function ($n = 7$); and information about available services ($n = 7$). Caregivers reported that CareHeroes was great ($n = 6$), easy to use ($n = 7$), and the tasks were straightforward ($n = 7$). Only three caregivers believed it helped them communicate with health care professionals, and only one caregiver reported taking the information from CareHeroes to a health care professional to discuss the health of the care recipient.

Four of the five participating PCPs completed a survey following the 11-week study period. The survey revealed that most PCPs anticipated CareHeroes would improve the quality of AD care ($n = 3$) and increase their professional satisfaction ($n = 3$). To a lesser extent, they reported that CareHeroes would improve caregivers' decision making about care ($n = 2$), improve their own clinical decision making about AD care ($n = 2$), and improve AD patients' ability to comply with prescribed treatment ($n = 2$).

For PCPs, the most common reason they communicated with case managers via CareHeroes was regarding patient treatment: two PCPs indicated that they communicated *moderately often* and one PCP indicated he/she used it for this purpose *frequently*. Two PCPs reported that they communicated *moderately often* using CareHeroes for the purposes of laboratory and diagnostic tests; reports of clinical values, such as blood pressure; and requests to complete forms and other paperwork.

All six case managers participated in the focus group. Case managers were asked about the utility of CareHeroes and their observations of caregivers' experiences with using CareHeroes. Case managers identified a number of CareHeroes functions as useful, including: valid information; useful caregiver self-assessment of depression and burden symptoms; and e-mail feature, community resources, and CareHeroes can improve communication between caregivers and providers. During the case manager focus groups, it was reported that caregivers found the self-assessments of depression and burden and the mood and behavior checklist to be the most helpful features of CareHeroes. As one case manager stated, "I have a particular [caregiver] who keeps getting reminded [automated response] that she should seek counseling assistance."

Case managers also made positive comments about the ease of use and accessibility of CareHeroes, such as, "It helps to see the graphs, to see trends."

Research Question 3

Participants completed open-ended questions that focused on recommendations and identification of obstacles for using CareHeroes. In response to an open-ended survey question regarding potential obstacles for using CareHeroes, one PCP identified a concern about having the time to use CareHeroes and another PCP commented that some older adults may not be technologically oriented.

In response to an open-ended survey question regarding potential obstacles for using CareHeroes, one caregiver stated, "Would be more helpful with weekly or monthly newsletters giving the caregiver tips/and helpful information for day-to-day coping. Also, there needs to be better access to organizations that can help with respite and day care." Another caregiver stated, "I have not used the Dashboard enough (only a few months) to realize or take advantage or understand all the benefits."

Critical feedback and recommendations for improvements were also identified through the case manager focus group. In general, the busy schedules of AD caregivers were identified as potential significant barriers to using the technology as part of their daily routine. As one case manager explained:

Well, when I talked to [the caregivers], they like [CareHeroes] and they feel like it's a good idea. It's just trying to figure out the tricks of the trade, I guess. They're trying to figure out what they can add into it. It's not that they don't want to do it, it's just that the time just slips away and they just forget. Because it's something new. With habits, it's tough to add a new [habit] into it. He wants to do it, it's just like everybody, time goes by so fast and he gets caught in the middle.

Other case managers reported specific situations their caregivers were dealing with that made it difficult for them to use CareHeroes effectively. For example, one stated:

One of mine, she had a left knee surgery and now she's having the right knee surgery. She definitely told me that she's too overwhelmed with that kind of stuff to enter into the system. The other one, she's out on emergency leave out of town.

Case managers suggested that by finding ways to minimize the amount of time it would take caregivers to use the technology may help them use it more. For instance, one case manager suggested incorporating push notifications as quick reminders to caregivers or a "hospitalization" alert button that would automatically send an e-mail to the case manager or PCP about a hospitalization, rather than requiring the caregiver to write an e-mail through CareHeroes.

During the case manager focus groups, a number of suggestions were made for adding features to CareHeroes that would make it more relevant for AD caregiving and overall AD care. One suggestion was to include instructional videos for caregivers that would educate them on specific tasks that caregivers often find difficult. Specific topics identified included: understanding AD and symptoms; food and nutrition for adults with AD; exercise and physical activity for adults with AD; bathing individuals with AD; using the Hoyer lift; positioning and avoiding bed sores; wound care; and relaxation and coping techniques for caregivers. Case managers also reported that linking CareHeroes with other telehealth technology, such as blood pressure, blood sugar, and mobility monitoring (for older adults at risk of wandering), would significantly increase the potential impact of the technology.

DISCUSSION

The current 11-week feasibility study demonstrated that triads of AD caregivers, case managers, and PCPs used CareHeroes to collect and share information about AD care recipients and reported being satisfied with the apps' navigation and multiple features. One half of caregivers reported CareHeroes made them more confident in determining solutions when new situations or problems arose and 70% *agreed* or *somewhat agreed* that navigating CareHeroes was easy and most tasks were easy to perform. These findings are promising for a brief study period and require further exploration.

Although there were few PCP participants, it is promising that they reported implementation of CareHeroes would improve the quality of care delivered and that their colleagues would support the effort to increase electronic communication between patients/caregivers and their providers. In addition, three of the four surveyed PCPs reported CareHeroes would improve their own professional satisfaction.

The brief 11-week feasibility study period posed challenges. Caregivers' fear of technology, their lack of having experience using it, and a lack of time to become accustomed to accessing and using CareHeroes apps was a concern identified by several case managers. These obstacles may be particular problems for Hispanic caregivers, who are digitally underserved by HIT (Hesse et al., 2005). In addition, when identifying potential caregiver study participants, several caregivers were identified as poor candidates for the project by

case managers, as they did not have computer access at home or had complex situations that occurred during the timeframe of the study.

Caregiver study participants were not highly proficient with using a computer. Two caregivers self-identified as *beginners* in regard to their computer skills and three caregivers rated themselves as having only *average* skills. It is anticipated that increasing use of CareHeroes would occur over time as users become familiar with the available resources, incorporate the technology into caregiving and patient management, and are able to work through technology-accessing barriers.

Despite these technological barriers, great potential remains for the use of technology to support caregivers of individuals with AD. The authors of three recent systematic reviews related to the use of technology to support AD caregivers concluded that despite the potential for technology to assist AD caregivers, much of the research in this area was underdeveloped (Boots et al., 2013; Godwin et al., 2013; McKechnie et al., 2014). Further, most of the formative research was conducted prior to the widespread use of smartphones. Advances in mobile app technologies combined with a greater understanding of the needs of AD caregivers should help promote the advancement of research in the area of technology-based support for AD caregivers.

LIMITATIONS

Although this was a feasibility study, there were a number of study limitations that should be considered when interpreting these results, such as the sampling methods, and requirements that caregivers had access to the Internet through a computer or Android smartphone and spoke English (despite the local population of AD caregivers being mostly of Hispanic descent). The feasibility study did not allow for resources to translate the CareHeroes apps; however, this translation is currently underway. In addition, the 11-week follow-up period may not have provided adequate opportunity for users to make use of the new health technology. The authors received feedback from caregivers and case managers that there was inadequate time to make CareHeroes part of the caregivers' routine. Therefore, a longer study follow-up period may have resulted in different study findings in both use and utility. However, there were many strengths of the current feasibility study, including engagement of stakeholders in the CareHeroes development process and the inclusion of a triad of users (i.e., caregiver, case manager, and PCP) in the evaluation process.

IMPLICATIONS

In a future investigation, the current authors plan to address the study findings and make refinements to CareHeroes. Development of caregiver educational videos in Spanish and English are currently underway, as suggested by case managers, with funding from the Hartford Change Agent Initiative. An interesting finding from the PCP survey with implications for nursing was that all of the PCPs reported that it would be helpful to have a nurse assist them with timely response in using CareHeroes. The use of a therapist or coach has been shown to be beneficial in the use of Internet programs for dementia caregivers (Boots et al., 2013). Nurses working with PCPs are well-positioned to educate and support

caregivers by leveraging the multiple CareHeroes features and resources. Therefore, in a larger future study, the current authors plan to train PCP office staff in the use of CareHeroes.

“Older adults’ use of technology, whether it be social networking, text messaging, use of the Internet, or use of mobile phones/tablets, is growing at an ever increasing rate” (CTA, 2014, p. 1). The current study focused on caregivers in their 50s who use the Internet but had varying levels of proficiency. HIT has great potential to empower and support patients and AD caregivers with daily decisions and challenges by providing information, the ability to exchange information with providers, access community resources, and connect with other caregivers. Most of the use of CareHeroes by caregivers in the current study was through the web app, rather than the Android smartphone app, which was primarily due to a lack of Android smartphone availability and lack of familiarity with downloading apps for a phone. However, smartphone app technology accessibility and use is increasing. Consequently, this may not represent a significant barrier in the future.

The current study findings also indicate caregivers used and valued the capacity to assess and document care recipient behavior disturbances and mood on a weekly basis. This assessment information would be helpful to nurses and other health care providers working with caregivers to manage care recipient disruptive behavior and resultant caregiver distress. Evaluation studies of caregiver HIT interventions should be conducted with patients at varying stages of AD, and value, including cost effectiveness, should be assessed.

CONCLUSION

The current study is the first, to the authors’ knowledge, to connect the key triad of an AD caregiver, home care case manager, and PCP and provide the capacity to share patient information. Further research is needed to establish the potential impact and potential cost savings for CareHeroes and increasingly accessible and emerging health technology to help address the needs of caregivers and their loved ones with AD.

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Figure 1.
CareHeroes caregiver welcome page for web and Android™ applications.

CareHeroes

Logout

Home Data by Case Manager Educational Resource Alert

701B Data

701B Form Update Date (YYYY-MM-DD)	2015-06-03
Name:	John Doe
Patient Code:	XXXX
Primary Language:	English
Address (Line 1) :	XXXX
City :	XXXX
Zip Code :	XXXX
How much assistance do you need with the following tasks?	
Bathing	Uses assistive device
Dressing	No assistance needed
Eating	Needs supervision or prompt
Using the bathroom	Needs supervision or prompt
Transferring	Needs assistance (but not total help)
Walking/Mobility	Needs total assistance (cannot do at all)
How much assistance do you need with the following tasks?	
Heavy chores	No assistance needed
Light housekeeping	No assistance needed
Using the telephone	No assistance needed
Managing money	No assistance needed

Figure 2.
CareHeroes web and Android™ applications 701-B data viewed by all users.

Figure 3.

CareHeroes action count over the 11-week study period (March 25, 2015 to June 10, 2015) for all users (i.e., caregivers, case managers, and primary care providers).

Note. An *action* is defined as an operation that a user is performing on the web or Android™ application, either through clicking a button or by following a hyperlink. A total of 349 actions occurred during the study period.

TABLE

Baseline Demographic Data of the Study Participants

Characteristic ^a	Caregivers (<i>n</i> = 11)	Case Managers (<i>n</i> = 6)	Primary Care Providers (<i>n</i> = 5)
Female (<i>n</i>)	9	5	1
Age (years) (mean, <i>SD</i>)	56.5 (13.5)	36.4 (13.5)	—
Race (<i>n</i>)			
White	3	4	3
African American	7	2	2
Hispanic	1	4	2
Other	1	—	—
Relation to care recipient (<i>n</i>)			
Adult child	9		
Spouse	2		
Education (<i>n</i>)			
Bachelor's degree (social work or psychology)		6	
Master's degree (social work or counseling)		2	
Licensure (<i>n</i>)			
Medical doctor			4
Family nurse practitioner			1

^aDifferent demographic data were collected from different groups of participants.