



Mobile Applications and Internet-based Approaches for Supporting Non-professional Caregivers: A Systematic Review

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PREFACE

Quality Enhancement Research Initiative's (QUERI) Evidence-based Synthesis Program (ESP) was established to provide timely and accurate syntheses of targeted healthcare topics of particular importance to Veterans Affairs (VA) managers and policymakers, as they work to improve the health and healthcare of Veterans. The ESP disseminates these reports throughout VA.

QUERI provides funding for four ESP Centers and each Center has an active VA affiliation. The ESP Centers generate evidence syntheses on important clinical practice topics, and these reports help:

- develop clinical policies informed by evidence,
- guide the implementation of effective services to improve patient outcomes and to support VA clinical practice guidelines and performance measures, and
- set the direction for future research to address gaps in clinical knowledge.

In 2009, the ESP Coordinating Center was created to expand the capacity of QUERI Central Office and the four ESP sites by developing and maintaining program processes. In addition, the Center established a Steering Committee comprised of QUERI field-based investigators, VA Patient Care Services, Office of Quality and Performance, and Veterans Integrated Service Networks (VISN) Clinical Management Officers. The Steering Committee provides program oversight, guides strategic planning, coordinates dissemination activities, and develops collaborations with VA leadership to identify new ESP topics of importance to Veterans and the VA healthcare system.

Comments on this evidence report are welcome and can be sent to Nicole Floyd, ESP Coordinating Center Program Manager, at nicole.floyd@va.gov.

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EXECUTIVE SUMMARY

BACKGROUND

Non-professional caregivers are an important source of physical, emotional and other support to ill or injured Veterans. With an increasing number of Veterans who require care and assistance for traumatic brain injuries (TBI), physical impairments, or other debilitating disorders such as post-traumatic stress (PTSD) and dementia, there is a greater growing demand for spouses, parents or other family members and friends to assume the role of caregiver. Electronic health applications and tools are increasingly available and have the potential to facilitate caregiving outside of traditional healthcare settings, especially in the context of the rising use of smartphones and mobile technologies. Lessons learned from prior consumer health information technology (CHIT) interventions could help inform the development of health-related mobile applications. CHIT applications are defined as electronic tools or technologies intended for use by consumers, by patients or family members, that interact directly with users for the management of their health or healthcare, and in which data, information, or other recommendations are tailored and/or individualized; the system may or may not link to a health professional or health system services. The Veterans Health Administration (VA) is currently developing mobile applications intended for use by seriously injured post-9/11 Veterans and their family caregivers enrolled in the Comprehensive Assistance for Family Caregivers program. This report was requested on behalf of the VA offices that are developing these mobile tools. The objectives of this report are the following: 1) to identify studies of CHIT applications that aim to support the needs of caregivers; 2) examine the usage and effects of CHIT applications on caregiver burden outcomes, and patient outcomes, clinical process measures, and healthcare utilization of interest; 3) discuss parallels that can be drawn from pediatric literature, and 4) identify gaps in the literature.

The key questions addressed by this systematic review are as follows:

Key Question #1. How does the use of consumer health information technologies (CHIT) by non-professional caregivers of adult patients with chronic illnesses or disability, or by such patients who rely on a non-professional caregiver, affect outcomes for caregivers, patients, clinical process measures, and healthcare utilization?

Key Question #2. What lessons can be learned from studies evaluating consumer health information technologies that specifically target the parents/caregivers of children?

Key Question #3. What are the major gaps in the consumer health information technology literature serving non-professional caregivers of adult patients with regards to technology development, availability, and/or evaluation?

METHODS

We conducted searches of multiple databases (MEDLINE[®] via PubMed[®], Embase[®], IEEE Xplore, AMIA Symposium Proceedings, Healthcare Information and Management Systems Conferences, Med 2.0, and Health 2.0) using terms for non-professional caregivers and mobile applications, including but not limited to terms for handheld/tablet computers, wireless/mobile

technology, iPad, cellular/mobile/android/smart phone, m-health, Internet based, SMS, text messaging, and informatics application. We obtained additional articles from systematic reviews, reference lists of pertinent studies, reviews, editorials, and by consulting experts. Reviewers trained in the critical analysis of literature assessed the titles and abstracts for relevance, and retrieved full-text articles for further review. We included studies if they utilized patient-facing and/or caregiver-facing interactive computerized health information technology, regardless of whether the device used in the study was mobile (smartphone, tablet, etc.) or stationary (desktop). We excluded non-interactive healthcare technology such as health education materials that are passively used. Given the broad scope of this topic as well as the presence of other reviews, we excluded studies focused on telephony, interactive-voice-response, synchronous telehealth interventions, and fixed home-monitoring technologies such as smart-homes, vitals-monitoring, GPS and other location-monitoring, and monitoring for patient falls.

We compiled a narrative synthesis of findings, highlighting studies that evaluated the effects on caregiver outcomes, patient outcomes, processes, healthcare utilization and describe the common characteristics and themes that emerged across studies and disease categories.

RESULTS

We reviewed 2,605 titles and abstracts from the electronic search, and identified 16 additional references through manual searching of reference lists or from input from technical advisors.

After applying inclusion/exclusion criteria at the abstract level, 388 full-text articles were reviewed. Of the full-text articles, we rejected 331 that did not meet our inclusion criteria.

Key Question #1. How does the use of consumer health information technologies (CHIT) by non-professional caregivers of adult patients with chronic illnesses or disability, or by such patients who rely on a non-professional caregiver, affect outcomes for caregivers, patients, clinical process measures, and healthcare utilization?

We included 31 publications reporting on 22 CHIT interventions that were being developed, piloted, or evaluated for their effects on caregiver outcomes, patient outcomes, healthcare utilization, or process measures. Of these, there were five RCTs. The remaining studies consisted of feasibility studies, usability studies, pilot tests, qualitative studies, and quasi-experimental studies. The small sample size, variety of outcomes measured, diversity of interventions, and methodologic weaknesses of this body of evidence preclude any definitive assessment of health outcome or utilization effects of CHIT. There was little data to inform the effects of CHIT on clinical process measures.

The majority of articles described interventions that provided educational content and one of several communication modalities: either online peer support groups, online access to providers through email, or general disease information and education.

Studies consistently found that the online peer support groups and chat rooms were both the most-used and most-valued components of any given website, application, or intervention. The asynchronous nature of these online communications facilitates participation in support

groups by mitigating some of the barriers of travel time, geographic separation, and competing priorities. In some studies, online communications provided access to a diversity of peers and clinicians that would otherwise not be available in many communities, particularly smaller town and rural environs. Anonymity was often perceived by users as an important feature of online support groups.

Several studies described how technical barriers or lack of familiarity with technology could limit accessibility of the intervention. Despite the numerous potential technical barriers, few studies reported the amount of technical assistance and training provided to users. Researchers speculated that older caregivers may be less likely to benefit from mobile applications because they are less likely to be users of handheld technology. A survey conducted in 2012 determined that while 70 percent of persons aged 65+ now own a cell phone, only 16 percent use their cell phone to access the Internet. Older caregivers may therefore require training in the use of the device or application, and may also benefit from applications with special accommodations for aging vision and manual dexterity, and their own chronic illness burden. Accommodations for language preference may enhance the utility of mobile applications for immigrant caregivers. Of note, no studies found that security or privacy concerns were a barrier to use of technology.

Key Question #2. What lessons can be learned from studies evaluating consumer health information technologies that specifically target the parents/caregivers of children?

We found 26 studies of 22 CHIT interventions in a variety of pediatric populations describing caregiver involvement with the intervention and/or caregiver outcomes. In all cases, parents were the caregivers being described. Cancer (4 interventions), traumatic brain injury (3 interventions), and diabetes (2 interventions) were the most common target conditions.

The largest group of studies described a multi-component intervention for children with traumatic brain injury and their parents, in which educational material was presented in interactive web sessions. The intervention was associated with reduced rates of parental anxiety and depression in three small, unblinded trials.

A larger trial involving asthma patients found that an intensive web-based intervention designed to improve parental and child knowledge of asthma reduced emergency room utilization. This intervention involved 44 animated lessons many covering real-life scenarios related to disease management and treatment adherence. Questions checked the user's comprehension.

Several studies also examined the role of online peer communication strategies. Parental users described benefits of peer support such as lowering the sense of isolation. While improving parental coping in some instances, users also pointed out the large volume of off-topic posts and posts about losing seriously ill children were detracting features.

Two studies evaluated text messaging interventions. One small trial in liver transplant patients found that a text-message medication reminder system involving children and parents reduced rates of biopsy-proven rejection. Another very large trial found that a simple text-message intervention in which parents received up to five weekly text messages increased influenza vaccination rates in a low-income population

Key Question #3. What are the major gaps in the consumer health information technology literature serving non-professional caregivers of adult patients with regards to technology development, availability, and/or evaluation?

The CHIT literature reflects a relatively new, developing field. Most studies described interventions in early development (ten studies) or pilot-tested (five studies) on a small scale. Only six studies were developed to evaluate health outcomes, but most of these were relatively small studies. There is a dearth of literature describing the health outcome effects of CHIT in larger populations. Some of the larger studies involved interventions, such as text messaging, which might be logistically simpler to deploy and test on a large scale. Almost no studies evaluated the actual implementation of interventions that had already been tested and found to be efficacious.

Reviewed studies were also not designed to develop a contextual understanding of the use of the intervention technology. At this time, there is not information to assess how these interventions fit into the day-to-day lives of caregivers. Additionally, there is relatively little information about how caregiver demographic characteristics impact the user experience. These are promising areas for future research; however, additional research is needed. For example, studies are needed to assess usage of mobile applications over time and to determine the most effective types of information, skills, and support that are needed to improve caregiver and patient outcomes.

The question of whether technology implementations should be designed for the caregiver or the patient as the end user is not answerable from the current literature, and may be best addressed by expert opinion and consensus.

DISCUSSION

There is a growing literature of CHIT interventions developed and tested for non-professional caregivers. Overall, a broad diversity of interventions has been identified, but the literature is insufficient to conclusively determine the effects of CHIT on caregiver/patient, healthcare utilization, or clinical process measure outcomes for a particular function or a specific condition. There is some evidence that CHIT interventions that target skill-building and stress reduction can be effective. Peer support and communication were the most commonly used intervention components; these functionalities were usually perceived as highly valuable. Though formal usability testing was not described in most studies, many studies described usage in more informal ways. Overall, the perceived utility of various technologies and their usage appeared to vary depending upon the caregiver target population. Some, but not all, studies described a user-centered design process. This may be particularly important for interventions targeting caregivers since they are burdened with self-care and the care of others, and the technology needs to fit into an often busy workflow.

It is unclear what CHIT interventions should be the focus of development in upcoming years. Multimodality interventions that combine different types of functions, applications, and devices (e.g., Internet, smart phones, text-messaging) may prove to be the most practical, given the rapid changes occurring in consumer technology development. Interventions focused on social support may reduce caregiver strain. Interventions, such as text messaging designed for cell phones

without Internet, can reach large and low-income populations, and may be able to improve specific health behaviors. No studies described integration of CHIT tools with the healthcare provider's electronic medical record. A move toward greater interoperability could offer caregivers a valuable opportunity to access their care-recipients' personal health data, as well as to input information that could be used by clinicians such as home medications, side effects, and patient symptoms.

CONCLUSION

There is a growing literature of CHIT interventions developed and tested for non-professional caregivers. Overall, a broad diversity of interventions has been identified; the majority were multi-component online tools intended to improve knowledge, skills and coping, and provide social support of caregivers. Many of these multi-component interventions offered communication functions such as online peer support groups, email access to clinicians such as nurse specialists, "ask an expert" forum where questions are answered, informational tools such as online libraries and consumer guides to specific diseases, and educational content promoting stress-relief, wellbeing, and coping skills. Given the heterogeneity of interventions and measured outcomes, as well as of the evaluative methodologies used, it is difficult to draw over-arching conclusions regarding the impact of these technologies on caregiver, patient, or utilization outcomes. Nevertheless, lessons learned about usability and user experience from these studies may offer some valuable insight to help guide ongoing CHIT development.

DEFINITIONS AND ABBREVIATIONS

The following abbreviations are used throughout this document:

| | |
|--------|---|
| ACTION | Assisting Carers using Telematics Interventions to meet Older Persons' Needs |
| AD | Alzheimer's disease |
| ADHD | Attention deficit and hyperactivity disorder |
| BSFC | Burden Scale for Family Caregivers |
| BSI | Brief Symptom Inventory |
| CAI | Caregiver Appraisal Inventory |
| CG | Caregiver, non-professional family members, friends, or community members |
| CHES | Comprehensive Health Enhancement Support System |
| CHIT | Consumer health information technologies, defined as interactive technologies that provide targeted or tailored health information and/or self-management tools or applications designed to support consumers' management of their health, health care, or health information |
| CR | Care-receiver/care-recipient, whether adult, child, or patient |
| CSES | Caregiver Self-Efficacy Scale |
| CSP | Customized Sleep Profile |
| CVA | Cerebrovascular accident, stroke |
| ER | Emergency room |
| HPN | Home Parenteral Nutrition |
| ICSS | Internet-based Caregiver Support Service |
| ICT | Information Computing Technology |
| ICU | Intensive care unit |
| IRC | Internet resources |
| IVR | Interactive voice response |
| KQ | Key question |
| NR | Not reported |
| OFPS | Online Family Problem-Solving |
| PCP | Primary care physician |
| PDA | Personal digital assistant |
| PDF | Portable Document Format, a file format used to represent documents for display on computers, smartphones and tablets |
| PIES | Prostate Interactive Education System |

| | |
|--------|--|
| PTSD | Post-traumatic stress disorder |
| QOL | Quality of life |
| RCT | Randomized controlled trial |
| SCL-90 | Symptom Checklist-90 |
| SMS | Short Message Service, a protocol that supports text messaging for mobile phones |
| SNF | Skilled nursing facility |
| SRG | Stress-Related Growth |
| SUS | System Usability Scale |
| SWLS | Satisfaction with Life Scale |
| TBI | Traumatic brain injury |
| TOPS | Teen Online Problem Solving |
| Tx | Treatment |
| VA | Veterans Affairs, United States Department of |
| VHA | Veterans Health Administration |
| WAMMI | Website Analysis and Measurement Inventory |
| WECARE | Web Enabled Caregiver Access to Resources and Education |