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

EXECUTIVE SUMMARY

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

With an increasing number of Veterans who require care and assistance for traumatic brain injuries (TBI), physical impairments, or other chronic conditions there is a growing demand for spouses, parents, or other family members and friends to assume the role of caregiver. Electronic health applications and e-health 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, 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. A CHIT tool may or may not link to a health professional or health system services. The VA is currently developing mobile applications that are 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.

Investigators with the VA Evidence-based Synthesis Program (ESP) Center in Portland, OR searched multiple databases and reviewed more than 2,600 articles and abstracts, with 57 meeting inclusion/exclusion criteria for this review. These articles were used to address the following questions:

Question #1

How does the use of CHIT by non-professional caregivers of adult patients with chronic illnesses or disability, or by patients who rely on a non-professional caregiver, affect outcomes for caregivers, patients, clinical process measures, and healthcare utilization?

The Evidence

Investigators included 31 publications reporting on 22 CHIT interventions; of these, five were randomized controlled trials. However, the small sample size, variety of outcomes measured, diversity of interventions, and methodologic weaknesses of this evidence preclude any definitive assessment of health outcome or utilization effects of CHIT.

The Findings

Studies consistently found that online peer-support groups and chat rooms were both the most used and valued components of any given website, application or intervention. The asynchronous nature (communication over a period of time not requiring same-time user collaboration) 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 small towns and rural settings. Anonymity also 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 on 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. Therefore, older caregivers may require training, and also may 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 the applications.

Question #2

What lessons can be learned from studies evaluating consumer health information technologies that target parents/caregivers of children?

The Evidence

Investigators found 26 studies of 22 CHIT interventions in a variety of pediatric populations describing caregiver involvement with the intervention and/or caregiver outcomes.

The Findings

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, with 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, as well as posts about losing seriously ill children that 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

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 Evidence

The CHIT literature, particularly targeted to caregivers, reflects a relatively new, developing field. Most studies described interventions in early development (n=10) or those that were pilot-tested on a small scale (n=5). Only six studies were developed to evaluate health outcomes, but most were relatively small.

The Findings

At this time, there is no information to assess how CHIT 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. The question of whether tools should be designed for the caregiver or the patient, or both, as end users is not answerable from the current literature, and may be best addressed by expert opinion and consensus.

Conclusion

There is a growing literature of CHIT interventions that have been developed and tested for non-professional caregivers. Overall, a broad diversity of interventions has been identified; the majority of these were multi-component online tools intended to improve knowledge, skills and coping, and to provide social support of caregivers. Many of these multi-component interventions offered communication functions, such as online peer-support groups; e-mail access to clinicians; "ask an expert" forums; 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 design, development and implementation.

To view the full report, go to <http://www.hsrd.research.va.gov/publications/esp/>.