

Pilot Test of a Computer-Based System to Help Family Caregivers of Dementia Patients

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Abstract.

Background: Family members absorb much of the care of dementia patients. The burden of care substantially impacts caregivers' health, further straining our healthcare system. By 2050, the incidence of Alzheimer's disease will more than double, increasing the numbers of family caregivers proportionally. Interventions that reduce their burden are needed to preserve their health as well as the viability of the healthcare system.

Objective: This paper reports on the development and feasibility testing of a computer-based system intended to improve the lives of caregivers. D-CHESS (Dementia–Comprehensive Health Enhancement Support System) allows users to obtain information, communicate with other caregivers, get help with care decisions, and share information with experts.

Method: Thirty-one caregivers were randomly assigned to an intervention group receiving D-CHESS for 6 months or to a control group receiving a caregiving book. Surveys at 0, 2, 4, and 6 months evaluated caregiver burden, family conflict, satisfaction with decisions, social support, loneliness, anxiety, depression, and coping competence.

Results: Survey findings suggest D-CHESS participants may perform better on measures of social support, anxiety, loneliness, and coping competence; the groups were equivalent on caregiver burden, decision satisfaction, and depression, and the control group reported less family conflict than the intervention. D-CHESS use data suggested enhancements to system design and content to increase awareness and use of various features.

Conclusion: This study suggests that D-CHESS has potential to positively impact family caregivers and that the system merits further development and investigation with a full-scale clinical trial.

Keywords: Alzheimer's disease, computer-assisted decision making, dementia, family caregivers, health information technology, psychological stress, social support, technological innovations, technology, telemedicine

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INTRODUCTION

In 2019, Americans with Alzheimer's disease numbered 5.8 million, a figure projected to rise to 13.8 million by 2050 due to longer life expectancies,

an aging Baby Boomer population, and the increasing incidence of the disease as people age [1]. The implications for the U.S. healthcare system are sobering, not only because of the rise in incidence but also the rising cost of care for each patient. Annual healthcare and long-term care payments for a person age 65+ with dementia (\$48,977) total more than three times the payments for a person age 65+ without dementia (\$13,976) [1]. By 2050, the national cost of care for those with dementia, if left unchecked, will increase from the current \$290 billion to an untenable \$1.1 trillion [1].

A large portion of individual care is absorbed by unpaid family caregivers. In 2018, 16.2 million family members provided 18.5 billion hours of care, or an average of 22 hours per week [1]. In addition, they paid an average of \$11,233 from their own resources for out-of-pocket expenses [1]. The cost savings to the healthcare system in terms of labor and expenses is significant, amounting to \$234 billion in 2018 [1], but the cost to caregivers themselves is a crisis in its own right. In addition to strains on time and financial resources, caregivers are often coping with serious threats to their quality of life, including loneliness, isolation, depression, and problems with employment, sleep, other family relationships, and susceptibility to disease [1–4]. The practical, emotional, and physical burdens of caring for loved ones with dementia far exceed the burden of care for non-dementia patients on every measure [1]. These burdens translate to greater healthcare needs on the part of caregivers themselves, costing an estimated \$11.8 billion in 2018 and further straining the system for all [1–3, 5, 6].

A number of recent studies have examined caregiver burden and how it may be reduced. Wawrziczny et al. suggest support programs with “preparedness, dyadic, and family modules” [7]. Schreve et al. recommend information technology-based interventions aimed at “alleviating the psychological burden and social isolation” of caregivers and “providing access to information and resources” [8]. In a review of existing interventions, Gitlin and Hodgson identify three elements common to those that are most effective: 1) the caregiver is actively involved with the intervention; 2) the intervention adapts to the needs of the family as the illness progresses; and 3) the intervention helps both caregiver and patient [9]. Overall, extensive research indicates that caregiver outcomes improve when caregivers have programs and tools that incorporate long duration [10, 11], assertive outreach [12], monitoring [13–15], prompts

[16–18], action planning [19–21], case management [22–24], and peer [25–27] and family [28, 29] support. In this article, we report on a pilot test that studied the effectiveness of an eHealth intervention employing these elements in addressing the psychological, social, and practical needs of family caregivers of patients with dementia.

MATERIALS AND METHODS

The intervention: D-CHESS

A family of eHealth systems known as CHESS (Comprehensive Health Enhancement Support System) has been developed over the last three decades by researchers in the Center for Health Enhancement Systems Studies at the University of Wisconsin–Madison. These systems employ web-based or mobile technologies to improve health and well-being, and several have been proven effective in randomized trials supporting patients with various conditions and diseases. Specifically, improvements have been shown in: 1) quality of life and costs of care for people with HIV [30], 2) quality of life and self-efficacy for women with breast cancer versus control and internet groups [31–33], 3) asthma control for young children [34], and 4) risky drinking among alcoholics [35].

Other versions of CHESS have aimed to support the caregiver rather than the patient. CHESS Lung Cancer (CHESS-LC) supported family caregivers of lung cancer patients by providing: 1) information, motivation, and skills training to support the caregiver from diagnosis through the first year of bereavement; 2) collection of health status data on the patient and caregiver; 3) alerts for the clinical team if a patient’s symptom exceeded preset thresholds; 4) access to new information; and 5) mechanisms for engaging family and friends. Results showed not only reduced caregiver emotional burden but also improved response to treatment, quality of dying, and length of patient survival [36].

Another earlier CHESS system was developed to support caregivers of dementia patients. Funded through grants from the Alzheimer’s Association and the Robert Wood Johnson Foundation, that system offered detailed information about dementia, personal accounts of how other caregivers coped, descriptions and locations of services that caregivers may need, and links to vetted online resources. Users could anonymously pose questions to experts, receive suggestions of resources for help, communicate

with other caregivers through facilitated discussion groups, and use decision aids to work through key issues. Caregivers ($n = 18$, all age 65+) who tested that early system indicated it provided needed information, peer support, and relief from isolation [37].

D-CHESS (Dementia–CHESS) is a website for use on computers or tablets that evolved from these earlier CHESS systems for caregivers. D-CHESS was designed to help with motivation, decision making, stress reduction, and access to services by allowing caregivers to obtain information and support without concern for location, distance, time, confidentiality, or education. Its development was informed by feedback from multiple focus groups held with caregivers of Alzheimer's disease patients and one-on-one needs assessments with individual caregivers. Among the many insights provided by this information was how new tracking and motion-sensing technologies might assist in reducing caregiver burden.

Table 1 describes the services provided by D-CHESS as well as external sensors offered to this study's participants. D-CHESS may be used as the disease progresses, for as long as needed, an element of successful tools for caregivers [10, 11]. In addition, D-CHESS services offer other elements proven effective in caregiver programs, such as assertive outreach, action planning, and peer and family support, as well as quality informational resources such as expert advice and vetted articles and websites.

Participants

Participants were unpaid family caregivers of patients with Alzheimer's disease. To be eligible, a caregiver needed to be: 1) an unpaid family member who was 2) the primary caregiver for a patient with dementia, 3) providing care in the patient's home, and 4) able to read English. We aimed to recruit 30 participants, following recommendations by Hertzog [38], and achieved a total of 31. All reported being white/Caucasian; their other characteristics are reported in Table 2.

As a measure of severity of dementia, Clinical Dementia Rating (CDR) scale scores were obtained at baseline from the subject database of the NIH-funded Wisconsin Alzheimer's Disease Research Center (WADRC) Clinical Core at the University of Wisconsin–Madison. CDR scores can range from 0 to 3 (0 = normal, 0.5 = very mild dementia, 1 = mild dementia, 2 = moderate dementia, 3 = severe dementia) and are based on semi-structured interviews with the patient and caregiver or other reliable source [40].

CDR data were missing from the WADRC database for one person in the D-CHESS group.

Procedures

An initial invitation letter was sent to caregiver partners of subjects with dementia in the Wisconsin Alzheimer's Disease Research Center Clinical Core study. The caregivers also received in-person invitations during their annual visit for the WADRC study. Interested caregivers could fill out and return a form or call CHESS research staff directly.

Eligible caregivers were sent the consent form and baseline survey with instructions to call CHESS staff once they received the documents. During that call, staff went through the consent form and answered any questions. If caregivers agreed to take part, they signed the consent, completed the baseline survey, and mailed both back to CHESS. When the consent and baseline surveys were received, participants were randomized to either the D-CHESS intervention ($n = 16$) or the control ($n = 15$) group. Participants were mailed subsequent surveys at 2, 4, and 6 months, for a total of four surveys.

From the original group of 31 participants, three did not complete the study because one patient was placed in memory care and two other patients died. In addition, two participants completed only two of the four surveys. Thus, 26 (83.9%) of the original 31 completed all surveys. Subsequently, one participant in the control group was a significant outlier on five of the eight outcome variables; this participant was removed from all analyses [39]. Therefore, final group sizes for analyses were 14 D-CHESS and 11 control participants.

The intervention group received access to the D-CHESS website for 6 months. These participants were also offered the use of three commercially available sensors: a Bluetooth tracker, a GPS location tracker, and a motion sensor. The Bluetooth tracker would help locate lost items such as keys; the GPS location tracker could be carried by a patient, allowing the caregiver to monitor the patient's location; and the motion sensor could be used to alert a caregiver if the patient entered specific areas of the home that could be hazardous. Four of the 15 caregivers chose to use one or more sensors.

These three sensors were included in the study as a result of feedback from focus groups with caregivers, who described situations for which they wanted help. We chose these particular devices because they address the largest number of scenarios mentioned

Table 1
D-CHESS services for family caregivers of patients with dementia

D-CHESS feature	Description
Home page	
Thought of the Day	Prompt that changes daily, targeting common concerns of caregivers (e.g., anxiety, financial issues, healthy eating) with links to resources. (<i>prompts, family support, quality information</i>)
Reading Room area	
Library Topics	Extensive on-site collection of informational readings on topics related to dementia and caregiving created by experts at UW, and links to relevant external websites vetted for quality. (<i>action planning, family support, quality information</i>)
FAQs	Searchable list of frequently asked questions and answers about dementia and related diseases, self-care and stress reduction, symptom and behavior management, financial and legal issues, medical care, end of life, and more. (<i>action planning, family support, quality information</i>)
Personal Stories	Real-life accounts from caregivers of family members with dementia, with prompts to explore 1) coping techniques, 2) in-depth descriptions of patient behaviors, symptoms, and caregiving stress, and 3) advice based on experiences. (<i>peer support, family support, prompts</i>)
Caregiver Tips	Quick tips from professional sources covering a broad range of issues, such as coping with the emotional side of caregiving, relating to the patient, and helping with everyday activities. Study participants also share their own tips. (<i>peer support, family support, prompts, quality information</i>)
Support area	
Discussion Group	Private, interactive online discussion group for caregivers of dementia patients for sharing and soliciting information, ideas, experiences, and support. (<i>assertive outreach, peer support, family support, prompts</i>)
My Journal	Private journaling feature for caregivers, with prompts for writing and reflection. (<i>prompts, action planning</i>)
Easing Distress	Collection of cognitive-behavioral, psychological, relaxation, and lifestyle strategies for coping with distress, including audio meditations, cognitive reframing exercises, and more. (<i>prompts, action planning, peer support, quality information</i>)
Tools area	
Weekly Check-In	Weekly caregiver report on measures of their own health and well-being, with responses tracked over time. When appropriate (e.g., indications of depression), specialists at UW follow up. (<i>assertive outreach, monitoring, prompts, case management</i>)
Placement Decision Guide	Step-by-step decision guide to help caregivers clarify situations and needs when considering placing a family member in specialized care. (<i>prompts, action planning, family support</i>)
Respite Planner	Interactive tool for 1) thinking through potential benefits and barriers to respite and 2) respite planning. (<i>prompts, action planning, family support</i>)
Action Planner	Interactive tool for creating a step-by-step plan for any change for caregiver or patient, such as bringing in help or changing doctors, establishing a budget, starting a relaxation routine, and more. (<i>prompts, action planning, family support</i>)
Finding Help area	
Ask a Specialist	Private two-way messaging between caregivers and Alzheimer's information specialists: 1) caregivers reach out at any time to request information and advice, 2) specialists initiate support when caregivers show need (e.g., depression) via responses on bi-monthly paper surveys. (<i>assertive outreach, prompts, case management, family support, quality information</i>)
Family & Friends	Updates and private messaging for family and friends of caregivers and their patients, available via sign-up. (<i>assertive outreach, prompts, peer support, family support</i>)
Community Resources	Alphabetical listing of health, social service, and other community organizations, as well as relevant websites, providing information and support to caregivers of dementia patients. (<i>peer support, family support, quality information</i>)
External sensors	
GPS Tracking	Location-monitoring via a tracker worn by the patient. (<i>monitoring, family support</i>)
Caregiver Alerts	Motion-activated sensors strategically placed (e.g., on doors) that notify caregivers when triggered. (<i>monitoring, family support</i>)
Item Finder	Bluetooth trackers, attached to items frequently lost, that emit a sound via a smartphone app when the item is sought. (<i>monitoring, family support</i>)

by caregivers. Insights gained with regard to the feasibility and acceptance of sensors by study participants will inform future development and grant submissions.

All D-CHESS participants already had their own computer and internet service, and they received in-home training for the system and (if used) sensor setup by CHESS research staff. If participants had

Table 2
Characteristics of D-CHESS and control group participants at baseline

Characteristic	D-CHESS (n = 16)	Control (n = 15)	Effect size
Caregiver age			n/a ^a
55–64	3	3	
65–74	7	9	
75+	6	3	
Patient age	No data	No data	n/a ^a
Patient CDR scores			
Mean (SD)	1.63 (0.99)	1.47 (0.88)	Cohen's d = 0.18
Range	0.5–3.0	0.5–3.0	
Caregiver relationship			n/a ^a
Spouse or partner of patient	15	13	
Adult child of patient	0	1	
Other relative	1	1	
Caregiver gender (female)	11	8	Cramer's V = 0.16, df = 1
Education	15.62 (2.09)	15.40 (2.26)	Cohen's d = 0.10 ^b
High school graduate	2	3	
Some college	3	2	
College graduate	8	7	
Graduate degree	3	3	

CDR, Clinical Dementia Rating. ^aTo calculate effect size for categorical variables, Cramer's V requires a cell size of 5 observations or larger [39]. In this case, the minimum requirement is not met. ^bTo calculate the effect size between groups, education was recoded as years of education as follows: high school graduate = 12, some college = 14, college graduate = 16, some graduate study = 17, master's degree = 18, PhD = 20.

technical issues with the website or sensors, they could call an 800 number for personal support from CHESS staff.

If caregivers scored above 10 on a depression assessment [41] in the paper survey (range = 0–27; higher scores signal greater depression), or if through D-CHESS they requested contact with a Wisconsin Alzheimer's Disease Research Center information specialist, a specialist would give them a call.

The control group received a limited intervention consisting of a book for family caregivers of dementia patients, *The 36-Hour Day* [42]. The book was mailed to the control group, and no other training was provided.

Ethics

Compliance with guidelines on human experimentation as well as study protocols were approved by the Institutional Review Board at the University of Wisconsin–Madison (submission ID 2016-0366). To protect confidentiality, only the project director had access to participants' names and addresses.

D-CHESS use

D-CHESS automatically collected use data, including: number of participants logging on, number of page views, specific services used, discussion group posts, data input to decision aids, and private

messages sent to the Alzheimer's disease information specialist at the Wisconsin Alzheimer's Disease Research Center.

Outcome measures

To test the impact of D-CHESS, we measured caregiver burden, family conflict, satisfaction with care decisions, social support, anxiety, depression, loneliness, and coping competence. Table 3 presents baseline outcome scores on the following measures for participants in both groups who completed all surveys.

Caregiver burden

A caregiver load scale [3] assessed objective caregiver burden with six items on a 4-point Likert scale (0 = don't have to do it, 3 = difficult, I need more help from others). The items incorporated both challenging behaviors and help needed with activities of daily living, including instrumental activities. A subjective burden question from the Caregiving Appraisal Scale [43] was added ("I can fit in most of the things I need to do in spite of the time taken by caring for this person"), measured on a 5-point Likert scale (0 = disagree a lot, 4 = agree a lot). All scores were recoded to a 10-point scale to equalize weight across scales, and an average was then calculated, reversing the subjective burden item. Higher values indicate more burden.

Table 3

Outcome scores at baseline for D-CHESS and control group participants who completed surveys at 0, 2, 4, and 6 months

Outcome	D-CHESS (<i>n</i> = 14) M (SD)	Control (<i>n</i> = 11) M (SD)
Caregiver burden ^a	3.36 (1.53)	3.36 (1.17)
Family conflict	0.28 (0.54)	0.27 (0.37)
Satisfaction with care decisions	3.29 (0.71)	3.17 (0.60)
Social support	2.43 (0.98)	1.89 (0.72)
Loneliness	0.83 (0.51)	1.03 (0.40)
Anxiety ^a	2.70 (1.58)	2.46 (1.69)
Depression	0.52 (0.44)	0.54 (0.54)
Coping competence	1.82 (0.44)	1.66 (0.42)

Higher scores indicate higher levels of the named outcome, whether positive or negative (e.g., more burden, more social support). ^aScores have been converted to 0–10 for analysis.

Family conflict

Twelve questions adapted from Aneshensel et al. [44] assessed family conflict on a 4-point Likert scale (0 = no disagreement, 3 = quite a bit). The Aneshensel et al. scales are based on surveys, observations, and interviews tapping stress across multiple dimensions of life, including family conflict, seeking help, and emotional support. An average score was calculated; higher scores indicate more conflict.

Satisfaction with care decisions

Satisfaction was assessed using the Satisfaction with Decision Scale [45], containing six items on a 5-point Likert scale (0 = strongly disagree, 4 = strongly agree). An average score was calculated. Higher scores indicate more satisfaction.

Social support

Caregiver's social support was assessed using the MOS Social Support Survey [46], consisting of 14 items on a 5-point Likert scale (0 = never, 4 = most of the time), with higher scores indicating more social support. In addition, seeking help was assessed using an adapted version of Aneshensel et al.'s [44] survey questions. This consisted of two items asking how much help caregivers received and how satisfied they were with the received help, both measured using 5-point Likert scales (how much help: 0 = no help, 4 = a lot of help; help satisfaction: 0 = not at all satisfied, 4 = very satisfied). The responses to all 16 questions were averaged to yield a single social support score. Higher scores indicate more social support.

Loneliness

Caregiver's loneliness was assessed using the UCLA Loneliness Scale [47], consisting of 20 items

on a 4-point Likert scale (0 = never, 3 = often). This scale was chosen for its brevity, the non-pejorative tone of the items, and its well-documented use with a broad age range, including the elderly. An average score was calculated, with items 1, 5, 6, 10, 15, 16, 19, and 20 reverse-coded. Item 9 ("How often do you feel outgoing and friendly?") was removed due to lack of variance in participants' answers, with over 54% of participants responding "often." Higher scores indicate more loneliness.

Anxiety

Caregivers' anxiety was assessed using multiple measures: 1) The Generalized Anxiety Disorder scale [48], consisting of seven items on a 4-point Likert Scale (0 = not at all, 3 = nearly every day); 2) two questions from Lawton et al.'s [43] subjective burden scale ("No matter how much I do, somehow I feel guilty about not doing enough for this person" and "Taking care of this person gives me a trapped feeling"), assessed on a 5-point Likert scale (0 = disagree a lot, 4 = agree a lot); and 3) a question assessing difficulty functioning ("If you checked off any problems, how difficult have these made it for you to do your work, take care of things at home, or get along with other people?"), using a 4-point Likert Scale (0 = extremely difficult, 3 = not difficult at all). All scores were recoded to a 10-point scale to equalize weight across scales, and an average was then calculated, reversing the difficulty item. Higher values indicate greater anxiety.

Depression

Caregiver's depression was assessed using the eight-item version of the Patient Health Questionnaire [41]. Responses were given on a 4-point Likert scale (0 = not at all, 3 = nearly every day). An average score was calculated for all items. Higher scores indicate more depression symptoms.

Coping competence

Ability to cope with the stress of caring for a family member with dementia was assessed with nine action-oriented items (e.g., "Made a plan of action and followed it") from Lawton et al.'s caregiver appraisal scale [43]. Responses were scored on a 5-point Likert scale (0 = never, 4 = most of the time), and an average score was calculated, with higher scores indicating greater coping competence.

Analysis plan

A 2 (time: baseline, month 6) \times 2 (study group: D-CHESS, control) repeated measures analysis of variance (ANOVA) was conducted to examine the effect of study group across time on each outcome separately. Therefore, eight 2 \times 2 repeated measures ANOVAs were run in total, one for each outcome.

RESULTS

Outcome measures

As expected due to the small sample size, all findings were nonsignificant ($p > 0.12$), but the effect sizes hint at what might be revealed with a sufficient sample size. Descriptive statistics and effects sizes for each outcome are reported in Table 4. Specifically, they suggest that the current version of D-CHESS, relative to the control group, may be associated with improvements in social support, anxiety, and coping competence and with preventing the worsening of loneliness.

However, the other four outcomes were not associated with practical improvement for participants in the D-CHESS group, relative to the control. Caregiver burden, depression, and satisfaction with care decisions worsened for everyone over the 6 months, regardless of study group. For family conflict, the small effect size indicates that the control group is associated with feeling less conflict after the 6-month

period while D-CHESS participants did not report any change (see Table 4).

D-CHESS use

Overall, participants continued to access D-CHESS throughout the study, with 100%, 50%, 71%, 71%, 57%, and 64% logging on during months 1 through 6, respectively (see Table 5).

As shown in Table 6, Support was the most visited area of the system, with 919 total pages viewed. This area showed the greatest decline in visits over time but still remained the most popular, logging the most pages viewed in the final month. Support was followed by Tools and Thought of the Day for amount of access. In terms of both number of visitors and pages viewed, use of Tools and Thought of the Day sustained or actually increased over the 6 months. These results are noteworthy because drop-off is typically a significant problem with online health tools [49–54].

DISCUSSION

This pilot study raises interesting hypotheses for future research and suggests changes for improving D-CHESS in preparation for a larger, controlled trial. For example, we expected a positive impact on decision satisfaction as a result of D-CHESS's decision-making and planning services, but found reduction in satisfaction over time in both groups.

Table 4
Repeated measures analysis of variance between study group and time

Outcome	D-CHESS ($n = 14$) Δ^a M (SD ^b)	Control ($n = 11$) Δ^a M (SD ^b)	Cohen's d^c
Caregiver burden ^d	−0.24 (1.24)	−0.13 (0.54)	0.09
Family conflict	0.01 (0.80)	−0.11 (0.68)	0.32
Satisfaction with care decisions	−0.24 (1.15)	−0.25 (1.23)	0.00
Social support	0.37 (0.89)	−0.07 (0.93)	0.68
Loneliness	0.00 (0.79)	0.19 (0.80)	0.54
Anxiety ^d	−0.28 (0.18)	0.05 (0.81)	0.28
Depression	−0.10 (0.77)	−0.09 (0.82)	0.00
Coping competence	0.21 (0.92)	−0.05 (0.75)	0.67

Higher scores indicate higher levels of the named outcome, whether positive or negative (e.g., more burden, more social support). ^aChange (Δ) was calculated as 6-month scores minus baseline scores. ^bChange in standard deviation was calculated using $SD_{\text{change}} = \sqrt{SD1^2 + SD2^2 - (2 \cdot \text{corr} \cdot SD1 \cdot SD2)}$. ^cEta squared was converted to Cohen's d using $d = 2 \cdot (\sqrt{\eta^2 / (1 - \eta^2)})$. ^dScores have been converted to 0–10 for analysis.

Table 5
General use of D-CHESS among all intervention group participants ($N = 14$)

Measure	Month 1	Month 2	Month 3	Month 4	Month 5	Month 6
n (%) logging on at least once	14 (100)	7 (50)	10 (71.4)	10 (71.4)	8 (57.1)	9 (64.3)
M (SD) page views per user	21.7 (59.6)	19.3 (37.2)	25.9 (35.6)	19.3 (21.0)	20.1 (35.3)	12.0 (14.2)

Table 6
Use of D-CHESS by service area

D-CHESS area visited	Month 1	Month 2	Month 3	Month 4	Month 5	Month 6	Study period
Thought of the Day							
<i>n</i> users (<i>N</i> = 14)	4	7	10	10	7	8	7.7 (54.8) ^a
Total pages viewed	23	31	51	32	28	24	189 (31.5) ^b
Reading Room							
<i>n</i> users (<i>N</i> = 14)	3	5	5	4	4	2	3.8 (27.4) ^a
Total pages viewed	16	19	23	23	14	9	104 (17.3) ^b
Support							
<i>n</i> users (<i>N</i> = 14)	14	5	7	9	6	6	7.8 (56.0) ^a
Total pages viewed	175	140	218	134	175	77	919 (153.2) ^b
Tools							
<i>n</i> users (<i>N</i> = 14)	5	7	10	9	8	9	8.0 (57.1) ^a
Total pages viewed	59	55	60	65	56	51	346 (57.7) ^b
Finding Help							
<i>n</i> users (<i>N</i> = 14)	3	5	2	4	2	3	3.2 (22.6) ^a
Total pages viewed	31	25	9	15	8	7	95 (15.8) ^b

^aAverage of months 1–6 and (in parentheses) percent of total *N*. ^bTotal page views during study and (in parentheses) monthly mean.

System use data indicate that the Tools area, where these services reside, was the second-most visited area of the site and that use actually increased over time, suggesting strong interest in or desire for help with decision making. User studies could help determine how D-CHESS's decision-making content could be more effective (e.g., more specialized, comprehensive, or in-depth).

With regard to family conflict, there are several family relationship and communication services on D-CHESS, but those services are located in the Reading Room and Finding Help areas, the two least accessed areas of the site. It is possible that revisions designed to enhance discoverability or encourage interest in these services, such as navigation changes and prompts, could increase visits to those services, which in turn could lead to improvements in family conflict outcomes.

That D-CHESS had no discernible effect on depression is consistent with results of other CHESS studies. The previous studies do show changes in quality of life, social support, and other dimensions that would lead us to expect depression to improve. It may be the case, however, that relieving depression requires more (e.g., medication, role playing and other components of one-on-one psychotherapy) than an online support system can provide [55].

We found a small trend toward reduction in caregiver burden over time for both groups, with D-CHESS performing better, but the effect size difference is close to zero and probably due to chance. Development aimed at this outcome might focus on peer support, which is shown to relieve burden [56].

The Caregiver Tips and Personal Stories services, where D-CHESS users could exchange practical ideas and share experiences with one another, are located in the Reading Room, one of the least visited areas of the site. Moving these services to the Support area may increase their visibility and use, potentially helping to reduce burden. In addition, use of all peer support resources might be increased with, for example, system prompts and other marketing and design changes.

The Support area, with peer-led discussion groups (typically the most frequently used service in CHESS systems), logged the most use but declined over time. Voice-controlled access via smart speakers and smart displays, a focus of our current efforts with CHESS systems, may help sustain use [57, 58]. That said, with only 14 participants in the intervention, the sample size was too small for the discussion group to reach critical mass, the number of participants needed to produce enough comments to keep a social network active [59, 60]. Lack of use of Caregiver Tips and Personal Stories may also be due, at least in part, to insufficient sample size.

In a larger study, where critical mass will be reachable, we predict higher use rates. Nevertheless, with so many services on D-CHESS (15, not including sensors), marketing, tutorials, and prompts to less-used but evidence-based services such as journaling (My Journal) [61] and cognitive behavioral therapy (Easing Distress) [62] are needed. Future development, incorporating artificial intelligence, will include features and functions that alert and remind users of underused services and provide automated training. D-CHESS has the potential to be smarter in other

ways, too. Other CHEAD systems use data collected on caregiver and patient status as well as natural language processing of user-entered text, such as discussion group posts and journal entries. Using these data appropriately, the system may be designed to detect and address caregivers' concerns before they become crises.

The design of the study itself appears practical and useful for a large-scale investigation. However, future research might employ a full or partial factorial design to further explain which D-CHEAD services have the most impact.

Technology advancements

Survey feedback from participants also suggests valuable changes to the technology platforms. First, the D-CHEAD system we tested was optimized for use on desktop and laptop computers. In our next round of development, we would adapt it as an app 1) for smartphones and tablets, for greater portability, and 2) for voice-activated smart speakers or smart displays, technologies currently being adopted at unusually high rates, including among the elderly and disabled [57, 58].

Second, we would include sensor technology with the D-CHEAD system rather than offer sensors as separate products, so caregivers would not need to make additional decisions for or against. Although every caregiver in the D-CHEAD group was offered the sensors, only four accepted them. Those who declined did so because they did not want the added burden of learning another technology, not because they did not see potential benefit.

Of the four who used them, three reported positive results. Caregivers who used the Bluetooth tracker to find lost items reported a reduction in both their own stress and patients' agitation. One patient frequently misplaced the TV remote and insisted the caregiver stop everything to find it. Another patient often lost keys. By affixing the tracker to the items, caregivers could instantly locate them by pushing a button on their phones and activating a sound from the tracker. The caregiver who used the GPS location tracker also reported reduction in stress. Her husband, in the early stages of Alzheimer's disease, took a bus to local events where he volunteered as a security guard. This level of independence was important to him. When he carried the GPS tracker in a pocket, the caregiver could see where he was at any moment, reducing her worry that he might get lost. The caregiver who tried the motion sensor sought to

use it as an alert if her husband attempted to enter the basement, where he had previously been injured. The implementation was not successful, because the family lived in a rural setting, where signal quality was unreliable. However, she understood its potential and was disappointed not to be able to benefit from it.

Limitations

Pilot studies, including this one, cannot test for statistical significance between groups in that they are underpowered, but they can help determine in a cost-effective way the feasibility of a larger study [63]. This pilot is valuable in that it explores the potential of a theory-based support system for caregivers of Alzheimer's disease patients, highlighting technical and practical issues for further development in preparation for more definitive study. We found moderate effect sizes for several outcomes, but a large randomized trial is needed to test significance between groups.

A further limitation concerns the demographics of the participants, who represent a fairly narrow swath of the population. In a full-scale study, we would aim for much greater diversity with regard to race and ethnicity, education, and gender.

Finally, in its current version, D-CHEAD does not incorporate several potentially beneficial technologies. First, the platform used (computer laptops) did not take advantage of smartphones, smart speakers, or smart displays, each of which offers capabilities that could increase the effectiveness of D-CHEAD. Second, only a small number of participants were willing to try sensors; as a result, data were insufficient to assess the practical utility of those devices.

Conclusion

Despite its limitations, this pilot test hints at the potential value of D-CHEAD to caregivers, which was expected given the findings from other CHEAD studies [29, 30, 32]. At the same time, the results point to possible development with regard to site design, content enhancements, and technological advances that could strengthen the system.

Perhaps most important is the potential for D-CHEAD to provide social support and ameliorate the isolation and loneliness present in caregiving roles [64]. Through discussion groups, caregiver tips, and personal stories, D-CHEAD currently offers ways to emulate the support achieved in traditional support

group settings—settings that are often inaccessible to caregivers because of their patients' constant needs, which make getting away for an hour or more difficult. Indeed, very few caregivers in this pilot attended support groups regularly, while they often reported anxiety and frustration as their loved ones' disease progressed. Having access to trusted peers and advisors through an online support group could increase knowledge, reduce feelings of isolation, and reduce stress, to the benefit of caregivers and patients alike [4, 65]. Accordingly, we aim to boost D-CHESS's support services in the next phase of development with enhancements such as prompts, online training, and improvements to site organization.

Overall, this pilot test suggests that D-CHESS may have the potential to help ease the stress of family caregivers, with positive implications for their own health. As our population ages and the incidence of dementia increases, straining both the healthcare system and our national economy, the need for solutions becomes increasingly urgent. Further development and investigation of D-CHESS with a full-scale clinical trial is merited.

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