

Helping Dementia Caregivers Manage Medical Problems: Benefits of an Educational Resource

American Journal of Alzheimer's Disease & Other Dementias[®]
2018, Vol. 33(3) 176-183
© The Author(s) 2018
Reprints and permission:
sagepub.com/journalsPermissions.nav
DOI: 10.1177/1533317517749466
journals.sagepub.com/home/aja



Sheryl Zimmerman, PhD^{1,2}, Philip D. Sloane, MD, MPH^{1,3},
Kimberly Ward, BA¹, Anna Beeber, PhD, RN^{1,4}, David Reed, PhD¹,
Christine Lathren, MD, MSPH¹, Bobbi Matchar, MSW⁵,
and Lisa Gwyther, MSW⁵

Abstract

Background/Rationale: Family caregivers of people with dementia must attend to medical care needs of their relative, yet few available resources address comorbidities in dementia. Consequently, caregivers feel ill-equipped when medical concerns arise. In response, an educational resource—Alzheimer's Medical Advisor (*AlzMed*)—was developed in 2 forms (website and book) and evaluated. **Methods:** Family caregivers (143 website and 51 book) used an educational resource that provides information on medical problems, vital signs, pain, dehydration, and the healthcare system. Data were collected at baseline, 3 months, and 6 months regarding confidence in sign/symptom management, burden, depression, and anxiety. **Results:** Caregivers reported significantly improved confidence and (for website users) decreased role strain. Anxiety and depression also decreased, although not significantly. Improved confidence related to a reduction in role strain and anxiety, and care recipients did not experience adverse events. **Conclusion:** An educational resource focusing on care of comorbid illness may benefit caregiver outcomes.

Keywords

dementia, caregiver confidence, caregiver burden, education, depression, anxiety, health events, healthcare

Introduction

As of 2016, more than 15 million family members and friends in the United States provide care for a person with Alzheimer's disease or a related dementia (ADRD).¹ Providing such care affects the well-being of caregivers themselves: almost 60% report high or very high emotional stress, 34% experience depression, 43% experience anxiety, and nearly 28% use a psychotropic medication—all of which are more common than among caregivers of persons without dementia.^{1,2} More so, caregiving burden negatively impacts the physical health of the caregiver and increases the likelihood that the person with ADRD may ultimately require admission into a long-term care residence.¹ For these reasons, providing resources and supports to caregivers of persons with ADRD is a high priority.

To date, numerous types of supportive interventions aimed at decreasing caregiver burden and increasing well-being have been tested. A recent systematic review classified these interventions into 5 main categories (psychoeducational, respite care, occupational therapy, cognitive behavioral, and other), and of these, psychoeducational interventions—which emphasize addressing caregiver gaps in disease-related knowledge or skill—are the most commonly used and have demonstrated positive impact on caregiver self-efficacy, depressive symptoms, and burden.³ Common educational topics include behavior management, general dementia

knowledge, communication, stress-coping skills and self-care, knowledge and use of community services, and social support.^{3,4}

Many caregivers are unable to attend in-person educational or support sessions, and for them, Internet-based services are more feasible—including interactive video learning, web-based courses combined with coach support or peer-support, learning modules with videos and written material, and educational material combined with chat forums and video conferencing.⁵⁻¹⁰ Although type, dosage, and duration of these interventions vary widely, recent systematic reviews of Internet-based supportive interventions find them to be a

¹ Cecil G. Sheps Center for Health Services Research, University of North Carolina, Chapel Hill, NC, USA

² Schools of Social Work and Public Health, University of North Carolina, Chapel Hill, NC, USA

³ Department of Family Medicine, School of Medicine, University of North Carolina, Chapel Hill, NC, USA

⁴ School of Nursing, University of North Carolina, Chapel Hill, NC, USA

⁵ Duke Family Support Program, Duke University, Durham, NC, USA

Corresponding Author:

Sheryl Zimmerman, PhD, Cecil G. Sheps Center for Health Services Research, University of North Carolina at Chapel Hill, 725 Martin Luther King Jr. Boulevard, Campus Box 7590, Chapel Hill, NC 27599, USA.
Email: sheryl_zimmerman@unc.edu

promising technique for increasing caregiver self-efficacy, confidence, and well-being.^{11,12}

Despite the relatively large number of psychoeducational interventions geared toward improving caregiver knowledge, skills, and coping, there is a dearth of support for caregivers as they attend to care recipients' medical needs. A recent report summarized the situation well: 40 million caregivers providing 37 billion hours of care worth more than US\$470 billion, facing "a different kind of caregiving . . . with caregivers managing chronic conditions for 5 or 10 years," which places enormous burden on them, physically, psychologically, and spiritually.¹³ Sixty percent of the caregivers now take on complex medical tasks once performed by doctors and nurses, due to their relative living longer, more complicated medication regimes, and shorter hospital stays (from 7.3 days in 1980 to 4.8 days in 2015), resulting in more medical care and oversight being provided at home.¹³

Indeed, the medical needs of older persons with ADRD are becoming more evident. An estimated 44% have congestive heart failure, 33% have chronic obstructive pulmonary disease, and 31% have diabetes.¹⁴ They have on average more than 8 chronic conditions in addition to ADRD, along with acute conditions that commonly require medical attention, such as injuries or infection.^{15,16} When combined with the challenge of cognitive impairment, this illness burden leads to higher healthcare resource use and expenditures, including emergency department visits and hospitalizations.^{15,16} In fact, adding a serious coexisting condition to a dementia diagnosis nearly doubles Medicare expenditures compared to those of persons with dementia and no serious coexisting condition.¹⁷ More so, and in the context of caregiving, interactions with the healthcare system are often driven by "non-dementia-related" medical issues^{16,18}—many of which are potentially avoidable¹⁹—highlighting the need for caregivers to better manage medical needs at home.

At the same time that caregivers are required to respond to a broad range of medical needs, they often lack the knowledge and skills to do so²⁰ and experience greater physical, emotional, and role-related burden as their healthcare responsibilities increase.^{21,22} Making the situation worse, virtually all caregiver resources that address symptom assessment and management focus on behavioral manifestations of dementia rather than on preparing caregivers to address new or worsening medical conditions. Meanwhile, the few interventions that do incorporate skill building or problem-solving around medical symptoms are resource intense (such as requiring in-person training from an expert)²³ or narrowly focused on a particular symptom, such as problems related to sleep.²⁴

As a result, the vast majority of caregivers miss opportunities to manage problems at home—which could perhaps avoid unnecessary healthcare use—and their lack of preparation increases their burden, strain, depression, and risk of injury.²⁵⁻²⁷ Consequently, not only have caregivers expressed a need for information about how to manage challenging medical symptoms,²⁰ but AARP has stressed that families must have access to healthcare information because they are directly

involved in making medical decisions,²⁶ and the American College of Physicians has noted that access to medical information and support can improve family-provider partnerships and prevent or delay hospitalization and nursing home placement.²⁸

In response to this resource gap, a team of geriatricians, gerontologists, and a gerontological nurse researcher developed the *Alzheimer's Medical Advisor (AlzMed)* website (and secondarily a book) to help family caregivers assess and manage medical needs at home (as appropriate) and more effectively work with healthcare providers. The intent of this resource was to be broadly applicable to a wide range of caregiver situations and easily accessible. The aim of this article is to briefly describe *AlzMed* and report on change in caregivers' confidence to address medical concerns, as well as change in caregiver burden, anxiety, and depression, following use of *AlzMed*. Given that most caregivers lack the basic information available on *AlzMed*, it was hypothesized that use of this educational resource would be associated with increased caregiver confidence and reduced burden, anxiety, and depression.

Methods

Study Participants

The project aimed to enroll 140 caregivers of people with dementia to evaluate the web-based intervention and 50 to evaluate the book. Web users were solicited by print and electronic postings; book users were solicited through print postings and support groups. To be eligible, the care recipient had to have a diagnosis of ADRD; reside in the community; not be on hospice or in a comatose state; and not be expected to transition to nursing home, assisted living, or hospice care within 6 months. Eligible caregivers had to be at least 21 years of age, the person most involved in care for their relative, and live with or visit their relative at least weekly. To be eligible to evaluate the web-based version, participants had to use the Internet (for any purpose other than e-mail) at least 3 times a week; book users had to not use the Internet more than twice a week; this criterion was determined in relation to the expected likelihood an individual would be to use the Internet versus a print resource. The sampling strategy was to enroll a range of white/nonwhite, college/noncollege educated, and spouse/non-spouse caregivers by establishing minimum and maximum recruitment goals across 8 strata that varied by these characteristics. All participants provided informed consent and received \$100 for their participation. Study procedures were approved by the institutional review board of University of North Carolina at Chapel Hill.

Data Collection and Measures

Caregivers were interviewed by telephone at baseline and at 3 and 6 months. After the baseline interview, caregivers were taught how to navigate the website (described in the next section) or provided with a copy of the book. Caregivers provided

information about themselves and their relative (eg, age, race, education, health, cognitive impairment [using the validated Cognitive Performance Scale])²⁹; new and worsening events experienced by their relative in the last 3 months; and their confidence to address medical concerns, as well as their burden, anxiety, and depression (ie, the study outcomes) at baseline and at 3 and 6 months. In addition, they were asked about use of the website or book, and website use was recorded electronically.

Caregiver Confidence

The 25-item Caregiver Confidence in Symptom Management (CCSM; $\alpha = .92$) scale includes questions regarding confidence in knowledge about signs/symptoms (5 items), management of cognitive signs/symptoms (6 items), management of medical signs/symptoms (4 items), and general medical management (10 items).³⁰ Items in the first 3 subscales asked about dementia-related behaviors (eg, agitation), mood changes (eg, depression), mental status changes (eg, confusion), new medical problems (eg, falls), and chronic disease (eg, diabetes); the fourth subscale included items about confidence related to enacting general behaviors, such as deciding whether to contact a medical provider and taking vital signs. All items are scored on a 5-point Likert-type scale, ranging from 1 (not at all confident) to 5 (extremely confident). The footnote to Table 2 provides more detail regarding the items. For example, items for the first 3 subscales asked “Overall, in providing care for your (relative), how true is it that you (a) knew enough about . . . ; (b) were confident in your ability to decide what to do concerning . . . ; and (c) were confident to take care of . . . ; new medical problems or events that may occur, such as falls, infections, or fever.”

Caregiver Burden

Burden was measured using the Zarit Caregiver Burden—short version, which includes 12 items rated on a 5-point Likert-type scale (0 = never to 4 = nearly always), yielding a summary score of 0 to 48.^{31,32} The measure creates 2 subscales: personal strain (9 items) and role strain (3 items). Sample items for personal strain include “because of the time you spend with your (relative) you don’t have enough time for yourself” and “do you feel angry when you are around your (relative)?” Sample items for role strain include “do you feel uncertain about what to do about your (relative)” and “do you feel you could do a better job in caring for your (relative)?”

Caregiver Anxiety

Anxiety was measured using the 7-item Generalized Anxiety Disorder scale, a short validated measure for diagnosing generalized anxiety; it generates a summary score ranging from 0 to 21.^{33,34} Each item is scored 0 = not at all to 3 = nearly every day. Sample items include “worrying too much about

different things” and “feeling afraid as if something awful might happen.”

Caregiver Depression

Depression was measured using the 9-item Patient Health Questionnaire depression scale, a validated measure scored 0 = not at all to 3 = nearly every day, yielding a summary score of 0 to 27. Sample items include “feeling tired or having little energy” and “feeling bad about yourself—or that you are a failure or have let yourself or your family down.”³⁵

Alzheimer's Medical Advisor Website and Book

Immediately after caregivers provided baseline data, they were provided a personalized log-in name and password and instruction on how to navigate the website—or provided with a copy of the book and assisted in its use by discussing an overview of its contents. The content and format were informed with input from family caregivers³⁶ and experts in web design. The *AlzMed* provides 3 types of information, as well as general information about dementia and caregiving.

- For each of 50 common medical problems, *AlzMed* includes facts about the problem, warning signs of a serious problem, what to do if fast action is necessary, how to prepare to contact a medical professional, and providing care for the caregiver (such as how to avoid injury when helping someone who fell); sample medical problems include constipation, falls, skin injuries, and worsening confusion.
- Videos providing instruction on taking vital signs and assessing and responding to pain and dehydration (included in the book as an accompanying DVD).
- Tips on working with the healthcare system, such as when contacting a medical office, visiting an emergency department or hospital, or contemplating a move to assisted living or a nursing home.

The content of the book was somewhat more concise than the website (eg, each medical problem fit 2 printed pages), but overall, the same material was provided, incorporated under the same headings. The material was organized into chapters (eg, one for common medical problems and one for working with the healthcare system), and graphics were included to facilitate identification of each type of problem—such as a hand with a Band-Aid, for skin injuries.

Every month, caregivers received a reminder of the availability of the web resource by way of e-mail. Book users did not receive regular reminders, but at study onset, they received a refrigerator magnet intended to serve as an ongoing reminder of the availability of the resource.

Analysis

Descriptive data (percentage, mean, and range) were calculated to describe caregivers and care recipients, and measures of internal consistency reliability (Cronbach's α) were derived for

all outcome measures (ie, confidence to address medical concerns, burden, anxiety, and depression). Mean scores were derived for each outcome at baseline, 3 months, and 6 months, and the significance in change in mean scores from baseline was calculated using a repeated-measures mixed model with a random effect for caregiver to produce tests of significance applying the Sidak adjustment for multiple comparisons. Associations between caregiver and care recipient characteristics and baseline scores were examined, as were associations between 6-month change in confidence and change in other outcomes. Associations were tested using analysis of variance, where the independent variable was categorical, and Pearson's *r*, where both variables in the relationship were continuous. To determine whether use of the website related to change in caregiver outcomes, an aggregate measure of dose was constructed that included the number of days the caregiver visited the website, the number of problem guides viewed, and the number of web pages accessed (ie, hits), over the preceding 3 months; the α of these items was .83. No measure of dose was available for book users. Multiple regression analyses were used to examine the relationship of dose with caregiver outcomes while controlling for differences in the baseline characteristics of caregivers by adding those characteristics as covariates. Analyses were conducted using SPSS for Windows, version 23.

Results

Web Version

A total of 161 eligible caregivers responded to the solicitation for the web-based resource; 143 (89%) were enrolled, provided baseline data, and learned how to navigate the *AlzMed* website; reasons for nonenrollment included burden of completing interviews ($n = 9$) and the study having met its recruitment goal for that stratum ($n = 9$). The recruitment goal of ≥ 5 participants per stratum was not met in relation to nonwhite, noncollege-educated spouses (1 recruited), and nonwhite, noncollege-educated nonspouses (3 recruited); all other strata had at least 5 participants, with the most being white college-educated nonspouses (68 recruited) and white college-educated spouses (41 recruited). Response rates were 95% at 3 months ($n = 136$; 6 were unable to be contacted and 1 requested to discontinue participation) and 85% at 6 months ($n = 121$; 4 were unable to be contacted, 8 moved to a nursing home or assisted living, and 3 died).

Caregivers were primarily white (83%), daughters (48%), who lived with the care recipient (76%), had a college degree (90%), and spent ≥ 15 hours online each week (50%). Care recipients were primarily female (61%) and had moderate dementia (61%); 50% or more required assistance with bathing, dressing, and medication use (see Table 1). During the study, caregivers visited the website an average of 6.2 (standard deviation [SD] 5.4) days over 6 months; they used 9.3 (SD 5.2) problem guides and averaged 63.1 (SD 49.3) hits.

Table 1. Characteristics of Caregivers and Care Recipients, Website and Book Users.

Characteristics	Website Users ($n = 143$), n (%) or Mean (SD)	Book Users ($n = 51$), n (%) or Mean (SD)
Caregiver		
Relationship to care recipient		
Spouse	49 (34%)	31 (61%)
Daughter	69 (48%)	14 (27%)
Daughter-in-law	12 (8%)	0 (0%)
Other	13 (9%)	6 (12%)
Lives with care recipient	108 (76%)	46 (90%)
Age	60 (11)	68 (11)
Female	122 (85%)	38 (75%)
College or graduate degree	128 (90%)	32 (63%)
Any medical training	32 (22%)	15 (29%)
Employed (full-time or part-time)	62 (43%)	17 (33%)
Race		
White	120 (84%)	34 (67%)
African American	20 (14%)	15 (29%)
Asian	3 (3%)	2 (4%)
Physical health		
Excellent/very good	93 (65%)	20 (39%)
Good	38 (27%)	19 (37%)
Fair/poor	12 (8%)	12 (24%)
Hours spent online each week		
10-15 hours	42 (29%)	0 (0%)
≥ 15 hours a week	72 (50%)	0 (0%)
Care recipient		
Cognitive impairment ^a		
Mild	10 (7%)	3 (6%)
Moderate	86 (60%)	25 (49%)
Severe	47 (33%)	23 (45%)
Years diagnosed with Alzheimer's/dementia	3.9 (3.1)	5.5 (4.5)
Age	78 (10)	79 (9)
Female	87 (61%)	26 (51%)
Physical health (rated by caregiver)		
Very good or excellent	48 (34%)	12 (23%)
Good	44 (31%)	18 (35%)
Fair	36 (25%)	12 (23%)
Poor	15 (11%)	9 (18%)
Needs hands-on/total assistance for		
Bathing	72 (50%)	21 (41%)
Dressing	74 (52%)	28 (55%)
Toileting	50 (35%)	11 (22%)
Transferring	46 (32%)	14 (27%)
Continence	62 (43%)	18 (35%)
Feeding	23 (16%)	7 (14%)
Medication use	99 (69%)	31 (61%)

Abbreviation: SD, standard deviation.

^aCognitive Performance Scale. Items include comatose, problem with short-term memory, cognitive skills for decision making, being understood by others, and activities of daily living self-performance in eating; impairment scores represent mild (0-1), moderate (2-3), and severe (4-6).

The internal consistency (Cronbach's α) of all outcome scales (4 confidence scales and the measures of burden, anxiety, and depression) ranged from .79 to .84. At baseline, overall mean confidence averaged 3.8 (SD 0.6) on a scale of 1 to 5

Table 2. Caregiver Confidence, Burden, Anxiety, and Depression Over Time Among Website Users.^a

	Baseline, Mean (SD)	3 Months, Mean (SD)	6 Months, Mean (SD)	P Value at 3 Months	P Value at 6 Months
Caregiver Confidence in Sign/Symptom Management (range 1-5)	3.8 (0.6)	4.1 (0.7)	4.2 (0.5)	<.001	<.001
Knowledge about signs/symptoms (5 items) ^b	3.7 (0.9)	4.1 (0.6)	4.2 (0.6)	<.001	<.001
Management of cognitive signs/symptoms (6 items) ^c	3.6 (0.9)	4.0 (0.8)	4.1 (0.7)	<.001	<.001
Management of medical signs/symptoms (4 items) ^d	3.7 (0.9)	4.1 (0.7)	4.2 (0.7)	<.001	<.001
General medical management/responsiveness (10 items) ^e	3.9 (0.7)	4.2 (0.6)	4.3 (0.6)	<.001	<.001
Burden (range 0-48)	22.8 (7.2)	22.4 (8.6)	21.9 (7.8)	.60	.58
Personal strain (range 0-36)	17.0 (7.1)	17.1 (6.1)	16.7 (6.7)	.96	.87
Role strain (range 0-12)	5.7 (2.5)	5.3 (2.7)	5.2 (2.6)	.08	.047
Generalized anxiety (range 0-21)	7.9 (5.1)	7.2 (6.9)	7.1 (6.2)	.31	.22
Depression (range 0-27)	5.6 (4.8)	5.0 (4.9)	5.2 (5.5)	.20	.62

Abbreviation: SD, standard deviation.

^aP values are based on the Sidak adjustment for multiple pairwise comparisons that were produced by a repeated-measures mixed model with a random effect for caregiver.

^bFive areas included knowing enough about dementia-related behaviors, mood changes, mental status changes, new medical problems/events, and problems associated with ongoing chronic disease. Higher scores are favorable.

^cSix behaviors included deciding what to do about dementia-related behaviors, taking care of dementia-related behaviors, deciding what to do when mental status changes occur, taking care of mental status changes when they occur, deciding what to do when mood changes occur, and taking care of mood changes when they occur. Higher scores are favorable.

^dFour behaviors included deciding what to do when new medical problems occur, taking care of new medical problems when they occur, deciding what to do when problems associated with chronic diseases occur, and taking care of problems associated with chronic diseases when they occur. Higher scores are favorable.

^eTen behaviors included gathering information a provider would want, making the decision to talk to a medical provider, talking to a medical provider, taking vital signs, understanding vital signs, assessing for pain, understanding what to do when in pain, assessing for dehydration, understanding what to do when dehydrated, and managing medical problems at home. Higher scores are favorable.

(corresponding to between somewhat and moderately confident; see Table 2). The mean burden score was 22.8 (SD 7.2; possible range 0-48), the mean anxiety score was 7.9 (SD 5.1; possible range 0-21), and the mean depression score was 5.6 (SD 4.8; possible range 0-27).

At baseline, caregivers with more medical training were more confident in their ability to manage medical signs/symptoms (4.0 vs 3.6, $F_{1,141} = 5.66$, $P = .019$) and engage in general medical management (4.2 vs 3.8, $F_{1,141} = 9.20$, $P = .003$). Further, caregivers who felt more confident in their knowledge about signs/symptoms, management of cognitive signs/symptoms, management of medical signs/symptoms, and general medical management reported less role strain ($r = -.17$ to $-.40$, $P = .047$ to $<.001$); those more confident in management of cognitive signs/symptoms also reported less personal strain ($r = -.25$, $P = .003$). In addition, time since diagnosis of dementia was positively associated with confidence in knowledge ($r = .18$, $P = .035$).

As shown in Table 2, confidence of the website users significantly improved in all 4 confidence measures at 3 and 6 months; overall scores averaged 4.1 to 4.2 (SD 0.5-0.7), translating to more than moderately confident. Also, role strain significantly decreased at 6 months, following a nonsignificant decrease at 3 months, and anxiety and depression decreased at both 3 months and 6 months, although the change in those was not statistically significant.

Correlational analyses (not shown) found that change in overall confidence and confidence in general medical management related to change in role strain at 3 months ($r = -.20$ and

$-.21$, $P = .022$ and $.017$, respectively). At 6 months, role strain correlated negatively with confidence in management of cognitive signs/symptoms ($r = -.29$, $P = .001$), general medical management ($r = -.24$, $P = .008$), and overall confidence ($r = -.27$, $P = .003$). Further, improved confidence in knowledge and management of cognitive signs/symptoms related to reduction in anxiety ($r = -.19$ and $-.32$, $P = .035$ and $.011$, respectively).

In terms of the relationship between dose and outcomes examined with multiple regression analyses, none of the confidence outcomes significantly varied by dose either with or without adjusting for baseline characteristics (although the relationship with dose was positive at 3 months for all confidence measures, and P values were $<.10$ for confidence in management of cognitive signs/symptoms, general medical management, and overall confidence). Dose was not associated with outcomes for burden, anxiety, or depression ($P = .30$ -.96).

Book Version

This sample ($n = 51$) had proportionately more minority caregivers (29% vs 14%) and caregivers without a college education (37% vs 10%) than those in the *AlzMed* website group (see Table 1). Similar to the results for the web-based version, caregiver confidence significantly improved at 3 and 6 months ($P < .001$), and only 1 subscale had a $P > .05$ (general medical management/responsiveness at 3 months; $P = .09$). Different from the web-based version, however, role strain was not lessened at either follow-up; however, at baseline, role strain was

lower than that of the web-based caregivers (13.1 [SD 6.7] vs 17.0 [SD 7.1]), which could relate to why no significant reduction in role strain occurred.

Discussion

Family caregivers of people with dementia are increasingly called upon to respond to medical needs, so caregiver resources must provide information and skills to manage medical issues; such resources have the potential to engage caregivers as active partners in health care and improve outcomes for both caregivers and care recipients.^{26,37} Our team developed and studied outcomes following use of an educational resource designed to fill the need for medical information, specifically targeted to caregivers of people with dementia. It provides information on more than 50 common medical problems, how to take vital signs and assess and respond to pain and dehydration, and tips on working with the healthcare system.

Regardless of the dose and method of administration (website or book), *AlzMed* users reported significantly improved confidence in sign/symptom management and (for website users) significantly decreased role strain (rated by items such as “do you feel uncertain about what to do about your relative” and “do you feel you could do a better job in caring for your relative”). Anxiety and depression also decreased, although not significantly so. Further, improvement in confidence related to a reduction in role strain and anxiety, suggesting that education may benefit caregiver outcomes.

It is important to recognize that findings related to role strain may have differed for book users compared to website users not only due to differences in the samples (in addition to demographic characteristics, book users reported less initial role strain) but also due to differences in educational content and implementation. For one, the material in the book was more concise than that on the website. Also, website users were regularly reminded to use the resource, but book users were not. These differences are important to note because psychoeducational interventions take such components into account.

To our knowledge, *AlzMed* is the first resource to provide comprehensive medical information and skill-based instruction specific to caring for people with ADRD. Other education-focused, web-based platforms do exist and have demonstrated improved outcomes for caregivers of persons with diverse chronic illnesses, including dementia.³⁸ For example, Beauchamp and colleagues found that a multimedia Internet platform delivering educational modules on coping skills and managing difficult behaviors reduced caregiver depression, anxiety, and strain, while positively impacting caregiver appraisal of their situation.⁵ Other similar multimedia interventions have demonstrated increased caregiver confidence and knowledge regarding skills and communication with family members, as well as decreased stress.³⁹ In terms of written educational materials, they have largely been examined within the context of broader multicomponent interventions rather than as a standalone intervention.⁹ All told,

although addressing caregiver’s emotional adjustment issues is important,⁴⁰ it is notable that none of these interventions provided medical symptom educational materials to caregivers, making it difficult to compare our results to those of multicomponent interventions.

The design of this study did not allow examination of whether use of these educational materials also resulted in improved outcomes for care recipients (eg, fewer medical visits or worsening conditions). However, throughout the study, death, emergency department use, and hospitalizations were tracked, and respondents were asked whether these events related to use of the website or book (eg, were due to delay in timely medical care based on information read in *AlzMed*). An external reviewer determined that none were attributed to use of the website or book, indicating that *AlzMed* has no apparent negative effects for the care recipient; however, the extent to which it actually benefits their care awaits further study.

In terms of promoting use of resources such as *AlzMed*, it is worth noting that at baseline, caregivers with self-reported medical training (eg, who described themselves as a registered nurse, speech pathologist, physical therapist, certified nursing assistant) were more confident in their ability to manage medical signs/symptoms and engage in general medical management than others; also, those with more confidence reported less role and/or personal strain. Results such as these are useful for outreach and indicate that caregivers with less medical training and confidence in sign/symptom management might most benefit from an educational resource. The majority of *AlzMed* users were college educated (90% who used the web and 63% who used the book), and fewer than one-third were African American; one might hypothesize even greater benefit among those with less education or who are otherwise less advantaged.

This study lacked a control group, and so it is possible—although unlikely—that all outcomes would have improved without access to these resources. Still, because it is comparatively inexpensive to maintain a website or purchase a book, there is good cause to promote the use of *AlzMed* to help family caregivers of people with dementia manage the medical problems they are sure to encounter.

Acknowledgments

The authors thank the family caregivers who participated in this study for their time and efforts and also their relatives with dementia who informed their experiences. The authors further thank Dr. Sam Weir who reviewed and evaluated the data related to potential adverse events and Ms. Julia Thorp for her diligent and sensitive efforts related to data collection.

Declaration of Conflicting Interests

The authors declared the following potential conflicts of interest with respect to the research, authorship, and/or publication of this article: P.D.S., A.B., and C.L. disclose royalties from the book developed from this research as a potential conflict.

Funding

The authors disclosed receipt of the following financial support for the research, authorship, and/or publication of this article: The work presented in this manuscript was funded by the National Institute of Nursing Research, Grant R01 NR014199.

References

1. Alzheimer's Association. Alzheimer's disease facts and figures. *Alzheimers Dement*. 2017;13:325-373.
2. Sallim AB, Sayampanathan AA, Cuttilan A, Chun-Man Ho R. Prevalence of mental health disorders among caregivers of patients with alzheimer disease. *J Am Med Dir Assoc*. 2015; 16(12):1034-1041.
3. Vandepitte S, Van Den Noortgate N, Putman K, Verhaeghe S, Faes K, Annemans L. Effectiveness of supporting informal caregivers of people with dementia: a systematic review of randomized and non-randomized controlled trials. *J Alzheimer's Dis*. 2016;52(3):929-965.
4. Sousa L, Sequeira C, Ferr e-Grau C, Neves P, Lleix a-Fortu M. Training programmes for family caregivers of people with dementia living at home: integrative review. *J Clin Nurs*. 2016; 25(19-20):2757-2767.
5. Beauchamp N, Irvine A, Seeley J, Johnson B. Worksite-based internet multimedia program for family caregivers of persons with dementia. *Gerontologist*. 2005;45(6):793-801.
6. Blom MM, Zarit SH, Groot Zwaafink RB, Cuijpers P, Pot AM. Effectiveness of an internet intervention for family caregivers of people with dementia: results of a randomized controlled trial. *PLoS One*. 2015;10(2):e0116622.
7. Ducharme F, Dube V, Levesque L, Saulnier D, Giroux F. An online stress management training program as a supportive nursing intervention for family caregivers of an elderly person. *Can J Nurs Informatics*. 2011;6(2):13-44.
8. Coulehan M. Impact of a web-based educational and peer-support intervention for dementia caregivers. Paper presented at: *Aging in America Conference—American Society on Aging*; 2011.
9. Lewis ML, Hobday JV, Hepburn KW. Internet-based program for dementia caregivers. *Am J Alzheimers Dis Other Demen*. 2010; 25(8):674-679.
10. Marziali E, Garcia LJ. Dementia caregivers' responses to 2 Internet-based intervention programs. *Am J Alzheimers Dis Other Demen*. 2011;26(1):36-43.
11. Boots LM, De Vugt ME, Van Knippenberg RJ, Kempen GI, Verhey FR. A systematic review of Internet-based supportive interventions for caregivers of patients with dementia. *Int J Geriatr Psychiatry*. 2014;29(4):331-344.
12. Parra-Vidales E, Soto-Pérez F, Victoria Perea-Bartolomé M, Franco-Martín MA, Muñoz-Sánchez JL, Parra Vidales E. Online interventions for caregivers of people with dementia: a systematic review. *Actas Esp Psiquiatr*. 2017;45(3): 116-126.
13. Special Report: Caregiving in America 2015. *AARP Bull*. 2015; 56(9):6-22.
14. Bentkover J, Cai S, Makineni R, Mucha L, Treglia M, Mor V. Road to the nursing home: costs and disease progression among medicare beneficiaries with ADRD. *Am J Alzheimers Dis Other Demen*. 2012;27(2):90-99.
15. Kuo TC, Zhao Y, Weir S, Kramer MS, Ash AS. Implications of comorbidity on costs for patients with Alzheimer disease. *Med Care*. 2008;46(8):839-846.
16. Zhao Y, Kuo TC, Weir S, Kramer MS, Ash AS. Healthcare costs and utilization for medicare beneficiaries with Alzheimer's. *BMC Health Serv Res*. 2008;8:108.
17. Maslow K. Dementia and serious coexisting medical conditions: a double whammy. *Nurs Clin North Am*. 2004;39(3): 561-579.
18. Griffith LE, Gruneir A, Fisher K, et al. Patterns of health service use in community living older adults with dementia and comorbid conditions: a population-based retrospective cohort study in Ontario, Canada. *BMC Geriatr*. 2016;16(1):177.
19. Lin PJ, Fillit HM, Cohen JT, Neumann PJ. Potentially avoidable hospitalizations among Medicare beneficiaries with Alzheimer's disease and related disorders. *Alzheimer's Dement*. 2013;9(1): 30-38.
20. Given B, Sherwood PR, Given CW. What knowledge and skills do caregivers need? *Am J Nurs*. 2008;108(suppl 9):28-34; quiz 34.
21. Wolff JL, Spillman BC, Freedman VA, Kasper JD. A national profile of family and unpaid caregivers who assist older adults with health care activities. *JAMA Intern Med*. 2016;176(3): 372-379.
22. Polenick CA, Leggett AN, Kales HC. Medical care activities among spouses of older adults with functional disability: implications for caregiving difficulties and gains. *Am J Geriatr Psychiatry*. 2017;25(10):1085-1093. doi:10.1016/j.jagp.2017.05.001.
23. Kunik M, Snow A, Wilson N, et al. Teaching caregivers of persons with dementia to address pain. *Am J Geriatr Psychiatry*. 2017;25(2):144-154.
24. Tewary S, Cook N, Pandya N, Mccurry SM. Pilot test of a six-week group delivery caregiver training program to reduce sleep disturbances among older adults with dementia- innovative practice. *Dementia (London)*. 2016:1-10. doi:10.1177/ 1471301216643191.
25. Dauphinot V, Ravier A, Novais T, et al. Relationship between comorbidities in patients with cognitive complaint and caregiver burden: across-sectional study. *J Am Med Dir Assoc*. 2016;17(3): 232-237.
26. Reinhard SC, Samis S, Levine C. Family caregivers providing complex chronic care to people with cognitive and behavioral health conditions. *AARP Public Policy Inst Insight Issues*. 2014; (93). Available at https://www.aarp.org/content/dam/aarp/research/public_policy_institute/health/2014/family-caregivers-cognitive-behavioral-AARP-ppi-health.pdf
27. Jennings LA, Reuben DB, Evertson LC, et al. Unmet needs of caregivers of individuals referred to a dementia care program. *J Am Geriatr Soc*. 2015;63(2):282-289.
28. Mitnick S, Leffler C, Hood VL; American College of Physicians Ethics, Professionalism and Human Rights Committee. Family caregivers, patients and physicians: ethical guidance to optimize relationships. *J Gen Intern Med*. 2010;25(3):255-260.
29. Hartmaier SL, Sloane PD, Guess HA, Koch GC, Mitchell CM, Phillips CD. Validation of the minimum data set cognitive

- performance scale: agreement with the Mini-Mental State Examination. *J Gerontol A Biol Sci Med Sci.* 1995;50(2): M128-M133.
30. Piggott CA, Zimmerman S, Reed D, Sloane PD. Development and testing of the Caregiver Confidence in Symptom Management instrument. *Am J Alzheimers Dis Other Demen.* 2017;32(7): 373-381. doi:10.1177/1533317517711247.
 31. Bédard M, Molloy DW, Squire L, Dubois S, Lever JA, O'Donnell M. The Zarit Burden Interview: a new short version and screening version. *Gerontologist.* 2001;41(5):652-657.
 32. Gitlin LN, Winter L, Dennis MP, Hodgson N, Hauck WW. Targeting and managing behavioral symptoms in individuals with dementia: a randomized trial of a nonpharmacological intervention. *J Am Geriatr Soc.* 2010;58(8):1465-1474.
 33. Spitzer RL, Kroenke K, Williams JB, Löwe B. A brief measure for assessing Generalized Anxiety Disorder: the GAD-7. *Arch Intern Med.* 2006;166(10):1092-1097.
 34. Löwe B, Decker O, Müller S, et al. Validation and standardization of the Generalized Anxiety Disorder Screener (GAD-7) in the general population. *Med Care.* 2008;46(3): 266-274.
 35. Phelan E, Williams B, Meeker K, et al. A study of the diagnostic accuracy of the PHQ-9 in primary care elderly. *BMC Fam Pract.* 2010;11:63.
 36. Fox D, Beeber A, Clark J, et al. Family caregivers advise Duke and UNC researchers. the caregiver (Newsletter of the Duke Family Support Program). 2014;33:5-7.
 37. Sadak T, Souza A, Borson S. Toward assessment of dementia caregiver activation for health care: an integrative review of related constructs and measures. *Res Gerontol Nurs.* 2016;9(3):145-155.
 38. Ploeg J, Markle-Reid M, Valaitis R, et al. Web-based interventions to improve mental health, general caregiving outcomes, and general health for informal caregivers of adults with chronic conditions living in the community: rapid evidence review. *J Med Internet Res.* 2017;19(7):e263.
 39. Kajiyama B, Thompson LW, Eto-Iwase T, et al. Exploring the effectiveness of an internet-based program for reducing caregiver distress using the iCare stress management e-training program. *Aging Ment Health.* 2013;17(5):544-554.
 40. Austrom MG, Lu Y. Long term caregiving: helping families of persons with mild cognitive impairment cope. *Curr Alzheimer Res.* 2009;6(4):392-398.