

E-Careonline: An Innovative Caregiver Education and Resource Internet-Based Intervention

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Premise of E-Careonline

- Visual demonstrations would aid caregivers in learning new techniques for caregiving.
- A monitored message board would provide caregivers with additional assistance and support.
- Caregivers would have 24/7 access at their convenience, not tie them to a specific time or place

Project Goals

- Develop an on-line educational and informational intervention for family caregivers
 - Based on CJE's previous experience with caregiver education and support interventions
 - Feasibility study (Iris, 2006) with previous version of the website
- Conduct a 12-month pilot study of users
 - Caregiver: Family or companions “providing assistance or care” to someone 60+, able to read and understand English

Study Design

- Convenience sample with random assignment to intervention vs. wait-list for comparison
- 3-month intervention period
- Pre/post assessment
- 57 participants
 - 31 in the intervention group
 - 26 in the comparison group

Recruitment

Contacted 90 organizations and individuals

- Social service agencies
- Day care centers, support groups, etc.
- Northwestern University Alzheimer's Disease Center Research Registry
- Presentations to caregivers and other groups
- Flyers, announcements in newsletters and synagogue bulletins
- Public service announcements

Assessment Tools

- Caregiver and care recipient sociodemographics
- Caregiver's situation
- Care recipient functional status (ADL & IADL) by caregiver report
- Anxiety: STAI Y-6
- Geriatric Depression Scale
- General Self-Efficacy Scale
- Family Caregiver's Self Efficacy for Managing Dementia Scale
- Zarit Burden Interview: Short Form
- Use of website
- Participant satisfaction

Caregiver Characteristics at baseline

(N=57)

- Mean age - 61.1 (Range: 39-86)
- 78.9% women
- 70.2% married
- 75.4% Caucasian, 19.3% African American, 5.3% Asian
- Most are well-educated, with moderate to high incomes

Providing care to:

- 41.0% spouses
- 54.1% parents or parents-in-law
- 4.9% siblings or others

Caregivers' Use of Internet at baseline (N=57)

- 83.6% had accessed information about caregiving via the internet prior to study
- 10.2% had participated in chat rooms, listservs or other online support for caregivers

Care Recipient Characteristics at baseline (N=61*)

- Mean Age - 78.4 (range: 60-95)
- Care recipients scored better on ADL's than IADLS (lower score is lower function)
 - Mean ADL score = 4 (out of 6)
 - Mean IADL score = 2.38 (out of 8)
- 89% of caregivers report that the care recipient has a cognitive impairment or memory disorder

* 4 participants caring for 2 people each

Caregiver Results at Baseline (N=57)

- Low depression
 - Mean score of 2.4 (range: 0-15, SD 2.50)
 - Scores of 5 or higher indicate possible depression
- Moderate anxiety
 - Mean score of 12.5 (range: 4-24, SD 3.40)
 - Higher score is more anxiety

Caregiver Results at Baseline (N=57)

- High self-efficacy & caregiving self-efficacy
 - SE: Mean score of 33.6 (range: 10-40, SD 4.92)
 - CG SE: Mean score of 68.8 (range: 10-100, SD 19.25)
 - Higher score is higher self-efficacy
- Low caregiver burden
 - Mean score of 17.6 (range: 0-48, SD 9.31)
 - Higher score is higher burden

Caregiver Results at Post-Test (N=48*)

- At *post* assessment, statistically significant differences in outcomes measures between intervention and comparison groups ($p < .001$)
 - Intervention group had less anxiety, less depression and higher caregiving self-efficacy than comparison group
- However, despite random assignment, there were significant differences between the groups at baseline as well

*8 participants from intervention group and 1 from the comparison group did not complete the study

Caregiver Results at Post-Test (N=48*)

- ANCOVA results: there were no statistically significant between baseline and follow-up scores on most outcomes
- Differences between treatment and control for caregiving self-efficacy approached significance, possibly because there were significant differences ($p < .05$) in the subscale for community support service use
- Ceiling effect: Participants tended to have high self-efficacy, with modest anxiety/caregiver burden and minimal depressive symptoms

Use of the Site

- Participants visited the site an average of 9.7 times over a three month period (1-36 visits)*
- Participants reported that a typical visit to the site was 15.9 minutes (mean)
- Visits to site ranged from 30 seconds to over an hour*

*Web tracking tool only allows tracking of group, not individual data (with the exception of number of visits to the site)

Use of the Site

- The site was visited at all times of the day*
 - More visits in the afternoon through late night
- Visits to the site increased after email reminders*

*Web tracking tool only allows tracking of group, not individual data (with the exception of number of visits to the site)

Use of Components of the Site (July-Feb)

- *Message board* was consistently the most visited page in early phase of study (July-December)
- *Moment for Yourself* was the second most visited, particularly the breathing exercises
- Other frequently visited pages
 - *Resources*
 - *Tips and Tools*
 - *Task breakdown module/video*
 - *Depression module*

Use of Components of the Site

(July-Feb)

- Later in the study period (December-February), participants more often visited the educational modules/videos, particularly:
 - Task Breakdown
 - Lifting and Transferring
 - Falls

Satisfaction Surveys (N=22)

- 90.9% felt more confident in ability to care for a loved one
- 77.3% felt more confident in their ability to get information that will help them care for a loved one
- 68.2% thought the web site was helpful
- 90.9% thought the site was easy to navigate
- 100% thought that having the site available was of benefit
- 100% would recommend the site to other caregivers

What caregivers liked most

- “Availability”
- “Seeing others’ situations”
- “Convenience”
- “Easy to use”
- “Will all make a difference in people’s lives”
- “Validation”
- “All of the information on the site”

Benefits of site

- “Someone saw an important need”
- “Very important is, ‘How do you save the caregivers?’”
- “Validation”
- “Another outlet for information”
- “Comfort and confidence”
- “Knowing that it’s there”
- “Knowing where to go (for help)”

Lessons Learned

- The site appeals to people in different types of caregiving relationships
- Volunteers to test the site tended to be:
 - Caring for someone with dementia for some time
 - Confident and in good mental health
 - People who had already sought information via the internet

Lessons Learned

- Participants valued:
 - Professional sponsor—credibility
 - Access to social worker
 - “Comprehensive,” well organized content
 - Idea of “one stop” site that links to other sites
 - Easy to navigate site
 - Sense of validation...both from just having the site available and from having access to the experiences of other caregivers via message board

New Name/New URL

- <http://www.CAREgivinghelp.org>
- Open to the public
- Linked to national organizations (Family Caregiver Alliance, Johnson & Johnson's Strength for Caring website)
- Caregiver "hits" from 27 states and 12 countries

CAREgivinghelp

Caregiving Assistance, Resources, and Education

- ▶ Educational Modules
- ▶ Resources
- ▶ A Moment for Yourself
- ▶ Message Board
- ▶ Frequently Asked Questions
- ▶ About Us
- ▶ Contact Us
- ▶ Disclaimer
- ▶ How to Use this Site

This site is brought to you by Council for Jewish Elderly. Since 1972, Council for Jewish Elderly has been providing quality programs and services to both Jewish and non-Jewish older adults and their families.

We are here for those caring for older people.

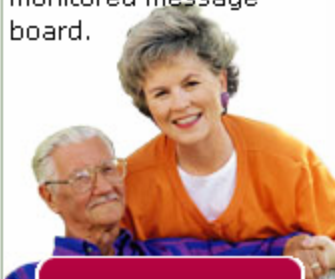
Education



Videos and other materials demonstrate specific skills or illustrate common issues you may face.

[Start Learning Now!](#)

Community



Ask the geriatric care specialist a question or share experiences on our monitored message board.

[Join the Conversation](#)

Resources

Access a variety of targeted Resources available to older adults and their families.

For those getting started or who have caregiving questions, visit the Frequently Asked Questions.

[Get Informed](#)

FEATURED TIP

Did you know that by visiting <http://www.medicarerights.org/webinars.html> you can download and view free educational "webinars" on a range of topics related to Medicare?

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Updates

- ▶ Information on a new prescription drug and health plan information website offered by Medicare