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Exploring the Effectiveness of an Internet-Based Program for Reducing Caregiver Distress Using the iCare Stress Management e-Training Program

Bruno Kajiyama[a], **Larry W. Thompson**[b], **Tamiko Eto-Iwase**[a], **Mio Yamashita**[a], **John Di Mario**[a], **Yuan Marian Tzuang**[c], and **Dolores Gallagher-Thompson**[d,*]

[a]Photozig, Inc., NASA Research Park, Moffett Field, CA 94035-0128, USA

[b]Department of Medicine, Stanford University, Fallen Leaf Lane, Los Altos, CA 94024-7211, USA

[c]Stanford Geriatric Education Center, Stanford University, Stanford, CA 94305, USA

[d]Department of Psychiatry and Behavioral Sciences, Stanford University School of Medicine, Quarry Rd MC5717, Stanford, CA 94305, USA

Abstract

OBJECTIVE—Determine if the online iCare Stress Management e-Training Program reduces stress, bother depression and poor life quality for dementia family caregivers (CGs).

METHOD—CGs (N=150) were randomly assigned to the iCare Condition (ICC) or to the Education/Information-Only Condition (EOC) for a 3-month periodChange in self-report measures of stress (PSS) (primary outcome), caregiver bother(RMBPC), depression (CES-D) and quality of life (PQOL) (secondary outcomes) was determined, along with usage of new information in one's own caregiving.

RESULTS—A mixed ANOVA revealed that change in perceived stress was significant for the ICC but not the EOC ($\underline{p} = .017$). Changes in the other measures were not significant. More caregivers in the ICC used the materials in their own caregiving situation than those in the EOC. Roughly one-third of the caregivers enrolled in the study dropped prior to completion.

CONCLUSION—Results are promising, but the high dropout is a concern. Future efforts to improve dropout rate and increase participant engagement are warranted. To our knowledge this is the first attempt to present an evidence-based intervention for CGs via the Internet.

Keywords

Alzheimer's Disease; caregiving; nonpharmacological treatments; Internet-based program; dementia

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Dementia is becoming a challenging health problem around the world as life span is increasing in nearly every country (Alzheimer's Disease International, 2009). Irrespective of geographic or cultural differences, much of the responsibility for the care of persons with dementia (PWD) rests with their family caregivers (CGs) (Family Caregiver Alliance, 2011; WHO, 2012). Evidence has accumulated in a number of countries documenting that caregiving can have negative effects on CGs' physical and mental health (Andren & Elmstahl, 2005; Beach et al., 2005; Coon et al., 2004; Prince et al., 2011; Sorensen, Duberstein, Gill, & Pinquart, 2006; Gallagher, Rose, Rivera, Lovett, & Thompson, 1989;

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[*]Corresponding author: dolorest@stanford.edu.

Vitaliano, Zhang, & Scanlan, 2003; Holland, Thompson, Tzuang, & Gallagher-Thompson, 2010; Holland, et al., 2011). Poorer health maintenance practices are more evident in CGs (Rabinowitz & Gallagher-Thompson, 2007), and a reduction in sense of well-being, increased social isolation, financial strain, and early placement of the PWD is frequently seen (Brodaty & Donkin, 2010; Carretero, Garces, Rodenas, & Sanjose, 2009; Etters, Goodall, & Harrison, 2008).

This portrayal has raised global concern about quality of life issues for CGs and the consequent economic burden for communities when caregiving is shifted from family to other social institutions. Evidence supports the argument that if CGs learn to deal more effectively with the stresses of caregiving, their quality of life will remain at a higher level. This in turn may delay placement of the PWD into institutional settings (Mittelman, Haley, Clay, & Roth, 2006). Evidence-based interventions for CGs have been developed (cf. Coon, Keaveny, Valverde, Dadvar & Gallagher-Thompson, 2012 for detailed review of US programs), but there are significant disparities in their availability among countries around the world (Alzheimer's Disease International, 2011; Prince et al., 2011; Gallagher-Thompson, et al. 2012; EUROFAMCARE, 2006).

Psychoeducational interventions (designed to teach adaptive coping skills to CGs) are the most widely studied, and improvement in level of depressive symptoms and stress have been reported (cf. Coon et al., 2012 and Gallagher-Thompson et al., 2007. Factors that limit access to evidence-based CG interventions, include: a) lack of knowledge and training among health care providers about these programs; b) low health literacy and/or language proficiency among CGs; and c) culturally-based beliefs that may counteract constructive help-seeking with dementia caregiving (Lai & Chung, 2011; Nielsen-Bohlman et al., 2004; Nikmat, Hawthorne, & Ahmad Al-mashoor, 2011; Parry & Weiyuan, 2011; and Gallagher-Thompson et al., 2012). To date, there have been few adaptations of evidence-based interventions to address these barriers. The web based program under investigation here, in particular, may address barriers making it difficult for caregivers to leave the PWD, such as transportation problems, lack of appropriate respite service, travel difficulty due to health or other disability problems, etc as well as cost of services.

The iCare program is an adaptation of the psychoeducational program called "Coping with Caregiving" (CWC) developed by Gallagher-Thompson and colleagues that aims to teach a set of core coping skills to CGs for stress management. These include: relaxation training; learning to increase everyday pleasant activities (including if possible some pleasant activities with the PWD); cognitive restructuring (of unduly negative appraisals regarding caregiving and themselves); and improved communication skills on how to ask for help effectively from family members and relevant community and medical institutions. Randomized trials involving this protocol have reported decreased depressive symptoms usually accompanied by a decrease in stress and specific caregiver bother (Gallagher-Thompson et al., 2003; Gallagher-Thompson et al., 2008; Au et al., 2009), which has been noted in protocol modifications for use in Hong Kong (Au et al., 2010) and Spain (Losada et al., 2004; Marquez-Gonzalez, Losada, Izel, et al., 2007) These studies offer the program in a small group format, thus requiring face-to-face contact over 8–12 weeks between CGs and trained interventionists in specific clinical or research settings. To offset costs and extend this service to one minority group Gallagher-Thompson and her colleagues developed a DVD that illustrated core skills of CWC in Mandarin Chinese with English subtitles. This DVD (and an accompanying workbook) was compared to an educational DVD (without a skill-training focus) in a randomized trial (Gallagher-Thompson et al., 2007; Gallagher-Thompson et al., 2010) and results showed a more prominent decrease in stress specific to caregiving but less change in level of depressive symptoms than was found in an in-home CBT model designed for Chinese-American CGs (Leung & Gallagher-Thompson, 2005;

Tang & Gallagher-Thompson, 2005; Wang & Gallagher-Thompson, 2005), which suggests that such interventions can be effective, while at the same time minimizing travel and schedule constraints.

Following this line a next step was to develop a protocol suitable for the the internet, which led to a collaborative effort with Photozig, Inc. Photozig, Inc. is a small R&D company that develops applications for digital video and photos, including health care applications, such as online training, media production and behavioral interventions. The company has research contracts with Stanford University to provide clinical expertise needed for special health care projects. Joint efforts between staff at Photozig and Stanford University led to the submission of a Small Business Research Grant Application to support the development of the iCare intervention. In the iCare intervention, we have modified CWC content and delivery mode to fit within a web-based format. The protocol is based on extensive feedback during early production efforts from an advisory group comprised of clinical and academic professionals and from numerous focus groups with dementia family CGs. The current iCare protocol (ICC) is an Internet-based program consisting of several action-oriented components including video-taped segments illustrating specific skills taken from the CWC protocol mentioned above.

In the present study we compared the ICC to an educational/informational condition (EOC) created specifically for this project with input from several national resources described below. The EOC served as a control for the impact of obtaining new information about dementia and what to expect in caring for dementia patients. It also controlled for the involvement with relevant information on the internet and for the general cognitive and experiential capacity required to “navigate” in complex internet materials. Although iCare is not the first Internet-based program for CGs (cf. Lewis, Hobday & Hepburn, 2010; Marziali & Garcia, 2011; and Powell, Chiu & Eysenbach, 2008 for other examples), it is the first to our knowledge that has modified an evidence-based treatment program for use on the Internet. Based on our past results with the CWC protocol we designated a measure of perceived stress as the primary outcome reported in ClinicalTrials.gov. Other secondary outcomes were specific caregiver bother, level of depressive symptoms and quality of life. The primary hypothesis is:

1. CGs in the ICC condition will report a greater decrease in general perceived stress than CGs in the EOC condition.

Secondary hypotheses are:

2. CGs in the ICC condition will show a greater decrease in the extent to which they are bothered by PWD problem behaviors compared to CGs in the EOC condition.
3. CGs in the ICC condition will report greater improvement in level of depressive symptoms than CGs in the EOC condition.
4. CGs in the ICC condition will show a greater increase in perceived quality of life than the CGs in the EOC condition.

METHOD

Procedure

CGs were recruited from the community through notices placed in family service agencies and other information and referral resources. Interested CGs contacted research personnel at Photozig, Inc. via e-mail or telephone. Following the initial contact, all communications with interested persons occurred online using questionnaires. Screening was a 2-step process. In the initial screening we asked if: 1) they were at least 21 years of age or older; 2) they were caring for an individual with a clinical diagnosis of some type of dementia; and 3) they had access to the Internet on any type of computer or had access to a DVD player. If they answered “yes” to these questions, they were asked to read the consent form and return a signed copy (either e-mail or regular mail) to indicate willingness to be in the study.

A questionnaire was sent to interested CGs to obtain: 1) additional demographic data; 2) amount of time and effort spent in caregiving tasks; 3) current clinical status of the PWD; and 4) their familiarity and competence in using the Internet. The Center for Epidemiologic Studies Depression Scale (CES-D) (Radloff, 1977) was also included to determine CGs level of current depressive symptoms. If CGs scored higher than 30 on the CES-D, which suggests a clinical level of depression, they were excluded from the study. These Participants were given referrals, and encouraged to seek professional help. CGs were also excluded if they were engaged in caregiving activities for less than an average of 8 hours per week, which is a minimal time used in many CG projects that focus on family caregivers.

Of the 354 individuals who responded to the study announcement, 12 (3.4%) did not meet all initial inclusion criteria and 2 (<1%) did not sign the consent form appropriately. Of the 340 remaining, 94 (27.6%) did not return enrollment forms required for the first screening, 60 (17.6%) did not complete all the questionnaires in the second screening, 35 (10.3%) had CES-D scores greater than 30, and one CG (<1%) later reported less than 8 hours per week spent caregiving. Persons, who started the survey process without completing it were prompted only twice via e-mail to complete it. Only a few responded to these prompts. The remaining 150 participants were enrolled into the study over a 7-month period on a rolling basis and recruitment was closed. The study was in progress from May, 2011 through January, 2012 in the US, but was not restricted to any region. Only 2 of the 150 assessments were completed off line. One CG attempted but failed to complete the online assessment successfully; the second refused to complete the assessment online.

CGs were randomly assigned to the ICC condition (N=75) or the EOC condition (N=75). They completed a set of baseline questionnaires prior to starting the intervention and again three months later (post-evaluation) at which time they were also asked how often they used the intervention materials provided, how helpful they were and whether or not they were using them in their own situation. No additional follow-ups were completed..

Of the 150 CGs who were enrolled in the study 47 (31.3%) were considered drop-outs. Of these, 7 (15%) withdrew because of time commitments or lack of interest, 28 (59%) did not complete post questionnaires even after several reminders, and 5 (11%) completed portions of them but were excluded because of significant missing data. Additionally, in 7 (15%) cases, the PWD had died during the course of the study. Twenty-nine of the dropouts were in ICC and 18 in EOC. The number difference in dropouts was due primarily to the number of care recipients who died (6 in ICC and 1 in EOC) and the number of CGs with extensive missing data in post forms (4 in ICC and 1 in EOC). All other dropout categories were comparable for both groups. See Figure 1 for a flow chart of the study procedure.

Participants

Table 1 provides sociodemographic data, indices of Internet familiarity and usage, and means and standard deviations (SDs) for the baseline outcome measures for both completers (N=103) and dropouts (N=47). There were no significant differences between these two groups on any variables.

About 97% of the CGs had used the Internet in the past to search for information, close to half used it for prior online training of some kind, and over 80% watched online videos.

Most CGs in the study (85%) were women in their late fifties with ages ranging from the mid-twenties to the early eighties; their PWD tended to be about 20 years older. More than 80% of the CGs had at least some college, and about 35% had completed some graduate school work. The majority (85 to 95%) were Caucasian; there were also African Americans (2.9%), Asian Americans (4.8%), Hispanic American (2.9%), Native American (1.9%) and Hawaiian/Pacific Islanders (0.9%) enrolled.

About two-thirds were caring for relatives with Alzheimer's Disease, 10% were caring for patients with vascular dementia, and the remaining 23% were CGs for persons with another form of dementia (see Table 2). Slightly more than half were caring for their spouse; 35 to 45% were caring for a parent and the remainder (10% or so) were caring for another relative or a non-relative(N=3; < 1%). Mean number of hours per week spent in caregiving activities was about 66 but the range was quite high (10 to 120 hours). Services provided ranged from transportation, shopping, and financial help to total personal care plus all other required services. On a 1–10 scale, both groups averaged approximately 7 discrete services being provided. The only significant difference between the two groups on any sociodemographic or baseline measures was that the mean age of the PWD in EOC was approximately 5 years greater than in ICC (p=.007).

Outcome Measures

Perceived Stress—The 10-item Perceived Stress Scale (**PSS**; Cohen & Williamson, 1988), derived from the 14-item scale by Cohen and colleagues (Cohen et al., 1983), measures overall appraisals of stress in the past month. It has been psychometrically tested and used in many studies with dementia caregivers. It assesses how unpredictable, uncontrollable, and over-loaded respondents find their lives. Items are rated on 5-point Likert scales (0=never and 4=very often). Internal consistency has ranged from .70 to .85 in prior research. Alpha for the current study was .559

Level of bother due to disruptive behaviors—We used the Revised Memory and Behavior Problems Checklist (**RMBPC**; Teri et al., 1992). It contains a list of 24 items (possible troublesome behaviors) that the PWD might have displayed during the past month. CGs are first asked whether or not the PWD did each on the list, and if so, CGs rate on a 5-point scale (0=not at all; 4=extremely) how much it "bothered or upset" them. Cronbach's Alpha for the current study was .880.

Level of Depressive Symptoms—Their presence and strength of depression were assessed using the Center for Epidemiological Studies Depression scale (**CES-D;** Radloff, 1977). This 20-item scale asks about the frequency of depressive symptoms (affective, psychological, and somatic) within the past week. It has adequate reliability as a measure of change with older adults (Hertzog et al., 1990). Estimates of internal consistency using Cronbach's alpha are high across a variety of populations (typically between .85 and .90). Alpha in the current study was .822.

Perceived Quality of Life (PQoL)—This measure contains 19 items describing level of satisfaction with needs and resources in various categories, and one global item reflecting level of happiness. It was developed using a normative sample of older individuals, and has been used in many studies investigating effects of chronic disorders on CGs perceived quality of life (Patrick, Danis, Southerland & Hong, 1988). Estimates of reliability and validity are high (Norburn, Patrick, Beresford & Stein, 1987). Cronbach's Alpha for the current study was .940

Interventions

iCare (ICC)—In the first year of this project, extensive interviews were conducted with caregivers and professionals in the field to develop and test each of the six modules included in the final web-based program. Table 3 provides a brief outline of the Introduction, the modules and the summary of future actions included in the intervention. The format for completing the ICC was configured so that the modules had to be completed in the order listed in Table 3. There were no minimum time constraints for completing a module built into the program, but participants were encouraged to practice specific assignments in each module over a 7- to 10 day interval before moving to the next one. The iCare program begins with an information segment about what "dementia" means and what are common problems associated with it. Then there are components on dealing with stress including techniques for relaxation, stress management, and challenging unduly negative thoughts about caregiving; behavioral activation (increasing everyday positive activities for oneself and the PWD); communication skills to improve help-seeking with family and community institutions as well as improving ability to relate to the PWD; managing difficult behaviors of the PWD; and finally, a review of "healthy habits" (nutrition and exercise) for the CG along with information on national resources they can consult for further on-going assistance.

A unique feature of iCare is that the information is presented in dynamic fashion through the use of embedded video clips illustrating how to do the various skills presented. Actors were used to portray different relationships (e.g., wife caring for husband with AD; daughter caring for mother; son trying to communicate with father) and different stressful situations that are common for most CGs. Typical CG responses are shown first, illustrating frustration, depression, guilt, fatigue etc., followed by more effective ways of handling or responding to the same situation which minimizes the above negative effects. This method of presentation enables CGs to identify with the characters who are role-modeling the various skills being taught. A DVD containing the entire program was also available to all ICC participants, in the event the internet was not available, but none used the DVD in completing the program. A workbook containing descriptions of exercises and relevant forms to expand practice opportunities was also provided to CGs in the ICC.. At the end of each module, CGs were asked to create their own individual "action plans" in the workbook requiring them to describe what they had learned by completing the module and relevant assignments and how they planned to use the information from that specific module in the future in their daily lives. .

Education/Information (EOC)—CGs assigned to the EOC were exposed to a website containing the similar navigational features, but the content focused on information about dementia, obtained from reputable national sources such as the ADEAR program of the National Institute on Aging and the national website of the Alzheimer's Association. In addition, links to certain video-taped information were provided (e.g., the Alzheimer's Project, developed by HBO in collaboration with the National Institute on Aging and the Alzheimer's Association)(The Alzheimer's Project, 2009). Written materials from various health agencies were also provided in a booklet format. Thus, extensive information using "state-of-the-art" media strategies was made available to these CGs, but without a format designed to enhance the development of specific skills to deal with stress from caregiving.

Data Analysis

All data reported in this study were obtained from self-report measures. No monitoring of web based activity by caregivers while using the materials was obtained. Data were analyzed using SPSS-19. Outcome measures were inspected to determine if assumptions for the general linear model were met. A mixed between-within ANOVA was selected for testing the primary hypotheses related to the four outcome measures. Separate exploratory analyses using number of hours spent in caregiving and age of PWD as a covariate were conducted using a mixed between-within ANCOVA. Correlations between the change in outcome measures and demographic variables were also obtained. Non-parametric procedures were also used in some of the analyses.

RESULTS

Primary Outcome Measure

Means and SDs for the outcome measures are reported in Table 4. Means for the PSS indicate that both groups reported a relatively high level of overall stress prior to intervention. A mixed between-within subjects ANOVA was conducted to determine the effect of ICC compared to EOC. A significant interaction between time from pre- to post-intervention and group condition was obtained (Wilks' Lambda =.945, F(1,101)=5.88, p=.017, partial eta squared=.055). Paired *t*-tests were obtained for change from pre- to post- in each group. There was no significant change in EOC (*t*(56)=0.231, p=.818), whereas the decrease in perceived stress in ICC was significant (*t*(45)=3.18, p=.003). The hypothesis concerning the effect of the ICC on general perceived stress wassupported.

Secondary Outcome Measures

The RMBPC, mean "reaction" scores to memory and behavior problems that actually occurred (caregiving-specific stress) shown in Table 3 suggest that both groups were only "somewhat bothered" by the behaviors of the PWD. A between-group comparison indicated that that there was no significant difference in the two conditions at pre-testing. A mixed between-within subjects ANOVA to determine the effect of participation in ICC compared to EOC was not significant (Wilks' Lambda =.966, F(1,101)=3.63 p=.060; two-tailed test). This was not consistent with our hypothesis that ICC participation would decrease CGs' reaction/experience of stress regarding common problems occurring during caregiving.

On CES-D at baseline, the mean for ICC was above 16 and the mean for EOC was above 14, suggesting the presence of depressive symptoms in both groups. This difference was not statistically significant (1.67(df, 101), p=.098). A mixed between-within subjects ANOVA was conducted to determine the effect of participation in ICC compared to EOC on the change in CGs' level of depressive symptoms. We found no significant interaction between time from pre-to post-intervention and group assignment (Wilks' Lambda =.987, F(1,101)=1.29, p=.259).

A brief inspection of the data for the Perceived Quality of Life Scale using SPSS 19 indicated that PQoL did not appear to be normally. Estimates of negative skewness resulted in z-scores greater than 2.5, and stem-and-leaf plots evidenced outliers in two of the conditions. A combined reflect-square-root transformation of the data was completed. This corrected the skewness and the norm Q-Q plots indicated that distributions now approached normality. A mixed between-within subjects ANOVA was conducted on the transformed data to evaluate the comparative effects of being in ICC vs. EOC. The interaction between the pre- to post difference and group assignment was not significant (Wilks' Lambda =.976, F(1,101)=2.48, p=.118).

Exploratory Analyses

Correlations were obtained to assess the association of change in the four outcome measures with demographic variables, and the effort and time spent in caregiving tasks. Results showed that the greater the number of hours spent in caregiving, the higher the baseline level of depressive symptoms as measured by the CES-D (r=.199, df=101, p=.044) and the less the improvement from pre to post-intervention on this measure (r=−.232, df=101, p=.019). A mixed between-within subject analysis was done, using this variable as a covariate. Results were the same for all analyses except for the RMBPC. This analysis yielded a change from (p=.06) to significant (Wilks' Lambda=.963, F(1,100)=3.98, p=.049, partial eta squared=.038). Thus, when the adjustment for hours spent in caregiving tasks is made, the ICC has greater impact than the EOC in decreasing level of specific stress associated with common behavioral problems evidenced by the PWD. Because the age of the PWD was significantly different between the two groups, we also did a mixed between-within subject ANCOVA using age of PWD as a covariate. Results of these analyses were comparable to the results obtained for the primary analyses. Finally, three non-relative CGs were removed from the database and the analyses were repeated. Results for all analyses were comparable to those obtained with the three participants included.

The mean number of times and the actual time per month CGs reviewed the materials provided were determined. Comparison of the two groups revealed that the EOC spent more total time using printed materials than the ICC group (means=3.3 hrs and 2.4 hrs per month respectively; Mann-Whitney U test p=.000), and the ICC group spent more time on the website (using it an average of 6.42 times per month compared to 3.13 times for the EOC; Mann-Whitney U test p=.000). All the materials were reported to be helpful by CGs in both groups. However, the ICC reported that the iCare workbook (mean=3.85, SD=1.19) was significantly more helpful than the printed resource materials used by the ECC group (mean=3.19, SD=1.11; t(93.26)=2.88, p=.005; Mann-Whitney U, p=.002). In response to the survey question, "I have used the new knowledge and skills in my own situation." 42% of the participants in the EOC reported that they did, whereas 78% of the ICC group affirmed that they were using the new information and skills in their caregiving situation. Fishers exact probability for this distribution of responses was p=.036. Usage and helpfulness measures were not significantly correlated with change in any outcome measures from pre to post. Including helpfulness and total time spent using materials as covariates in a mixed between-within ANCOVA yielded results comparable to results in the primary analyses.

DISCUSSION

This study evaluated the effectiveness of an online iCare Stress Management e-Training Program to reduce stress and stress-related symptoms in caregivers with the required cognitive and material resources to work on the internet.. CGs in the ICC experienced greater improvement in overall stress than CGs in the EOC which supports our primary hypothesis. While similar trends were observed in secondary outcome measures (i.e. conditional bother, depressive symptoms and perceived quality of life), the treatment group by time interactions for these three measures were not significant. However, correlations between the outcome measures and possible predictors showed that the greater the level of effort expended in caregiving, the less improvement in level of depressive symptoms from pre to post, and when this variable was entered as a covariate in exploratory analyses the treatment by time interaction for conditional bother was significant. Mean comparisons showed that pre-post improvement in how bothered the ICC group was by the care recipients' problem behaviors was highly significant, whereas there was no significant change in this variable for the EOC group. Similar non-significant trends were seen in the level of depressive symptoms and the perceived quality of life. These results are promising and we are encouraged that further modified explorations with this modality may yield greater support for our secondary hypotheses. We reasoned that an Internet-based program could potentially reach a large number of CGs who may not have access to helpful resources because of logistical constraints, and if the ICC were more effective than the EOC, this would encourage future work "translating" evidence-based programs into other formats that are more user-friendly and accessible to a broader range of CGs. To our knowledge, this is the first study of its kind that attempted to expand the reach of current evidence-based programs for CGs into a web-based program.

The iCare condition was developed to use the Internet as a medium for teaching a specific set of coping skills that were shown in prior research to help CGs manage their stress and handle common caregiving situations more effectively. The ICC was compared to an EOC that also used online resources to provide compelling information about the causes and course of dementia as well as the availabilty of resources to ease the burden of family caregiving, but without the focus on the practice of specific techniques to deal with the stresses of family caregiving.

Although the results were promising they were not as robust or extensive as we had expected. CGs in ICC reported greater satisfaction with the printed materials they were provided compared to those in EOC, reported spending more time on their website and a significantly larger proportion reported using the iCare materials in their own caregiving situation These findings suggest that the various resources in the program were being-utilized. However, as noted earlier there was no association between usage and how helpful the ICC materials were, which raises questions about what were the active ingredients in the treatment package...

Future work should explore how and to what extent specific skills (such as relaxation techniques) are actually being utilized to help deal with caregiving stress. However, the extent to which CGs reported that they were reviewing and re-reviewing materials was low (despite the easy availability of internet access) and this may have contributed to the absence of more significant findings. A national survey of 6,369 US adults found that 63.7% said they looked up health information on line before talking with their physicians (Hesse et al., 2005) but frequency of repeated use of the internet to acquire or review health information has not been studied. Some limitations of the present study should be noted. The sample included primarily late-middle-aged Caucasian women with some college education, who were familiar with computers and using them to obtain information through the Internet. Thus, they may not be typical of most older dementia CGs, who are from a cohort with minimal exposure to computers and the Internet. Due to limited gender, ethnic, and racial diversity in the sample, we do not know the extent to which men, minority groups, and/or CGs of more diverse socio-cultural backgrounds would benefit from the iCare program. Other research has suggested that psychoeducational programs can be effective with racially and ethnically diverse CGs (Olazaran et al., 2010; Sorensen et al., 2006; Losada Baltar, Izal Fernandez de Troconiz, Montorio Cerrato, Marquez Gonzalez, & Perez Rojo, 2004; Au, Li, et al., 2010; Burgio et al., 2009; Hepburn, Lewis, Tornatore, Sherman, & Bremer, 2007; Hepburn, Tornatore, Center, & Ostwald, 2001; Ostwald, Hepburn, Caron, Burns, & Mantell, 1999; Belle et al., 2006; Gallagher-Thompson et al., et al., 2003; Gallagher-Thompson, Gray, Dupart, Jimenez, & Thompson, 2008; Gallagher-Thompson et al., 2007; Gallagher-Thompson, and Wang et al., 2010). It remains to be seen how effectively diverse groups of CGs can be engaged in a program that is solely Internet based. Second, although effects in the expected direction were found, results are modest in comparison to other studies that used face-to-face interventions. Third, there was a relatively high rate of CGs being ineligible. The majority of these did not follow through, either by not returning enrollment materials or not completing baseline questionnaires. This further suggests that we had a select sample of CGs who were motivated to participate and to learn skills. Additionally, the drop-out rate (about 31%) from this study was high compared to other CG intervention studies reporting around a 20% drop out rate (Gallagher-Thompson et al., 2012)This suggests that other problem areas of importance to these CGs were not available in the program.. Fourth, the data obtained were all self-report. No on-going monitoring of program use was obtained. CGs were required to complete all items in a module before proceeding to the next, but we have no data on how much time and effort was spent on each exercise independent of self-report. Future work should include increased monitoring of CGs' use of the program along with opportunities to interact with CGs, and provide feedback as they complete required exercises.

Feedback from some participants support the conclusion that limited interaction with project staff, or with other caregivers, may have been a deterrent to greater engagement in the program. Future work should focus on increasing the interactive capabilities with staff and other caregivers. Inclusion of chat rooms facilitated by professional staff could be helpful, along with more detailed monitoring and availability of help lines would likely increase participation and consequent benefits. In this regard cost factors need further consideration in providing a feasible resource that will maximally effective.

Nevertheless it appears that a program like iCare can be beneficial to CGs who are motivated to participate, Internet-savvy, and do not require interpersonal interaction with health care providers. Future research should focus on broader outreach so that more diverse CGs can be enrolled, and their responses studied. In that way, we can hopefully build on the knowledge gained from iCare and expand Internet-based programs to be more responsive to the needs of a broader range of caregivers in the future.

As a final note, Photozig, Inc. has made this program available for purchase through Amazon in a DVD format. The cost is reasonable (about $25.00 new) and appropriate disclaimers are included.

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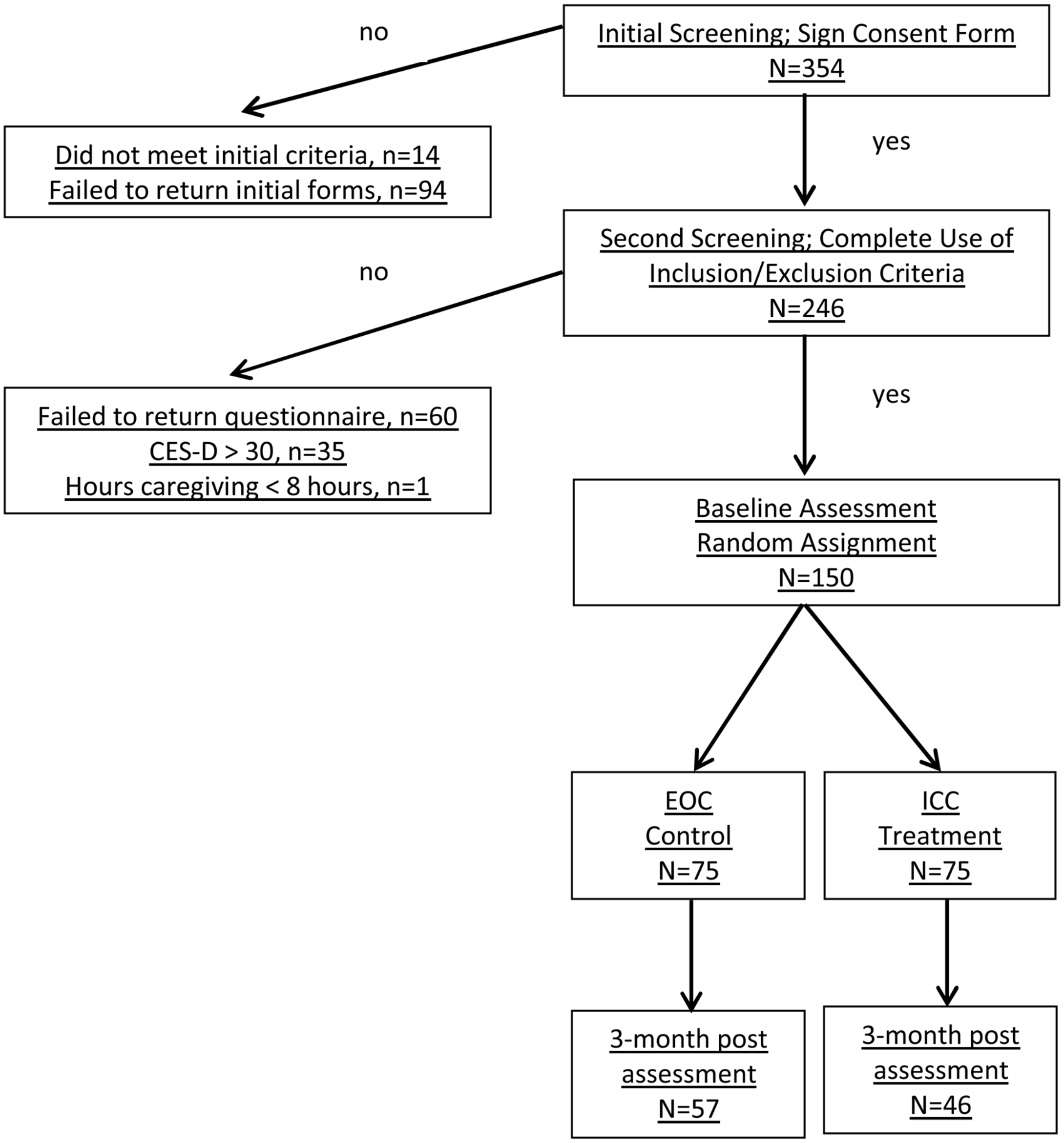

Figure 1.
Flow chart of study procedure

Table 1

Socio-demographic, Health Characteristics and pre-intervention outcome variables for Participants Grouped According to Whether they Completed the Study or Dropped Out

	Completers (N=103)		Drop-Outs (N=47)[**]		*t*, chi square or Fisher's exact
Variable	**Mean**	**SD**	**Mean**	**SD**	
Age of Caregiver	56.12	11.97	56.17	10.07	*t*(148)=0.21, *p*=.983
Age of Care Recipient (PWD) [*]	77.67	10.07	78.00	9.51	*t*(145)=1.20, *p*=.231
Services Caregiver provides [a]	7.39	2.36	6.68	2.83	*t*(148)=0.85, *p*=.327
Number Hours Care Per Week	66.77	40.52	67.34	41.16	*t*(148)=0.08, *p*=.936
Perceived Stress Scale	16.38	3.89	16.73	4.18	*t*(148)=0.62, *p*=.623
Caregiving Specific bother[b*]	1.10	0.67	1.13	0.73	*t*(146)=0.25, *p*=.804
CES-D Depressive symptoms[c]	15.226	7.95	17.34	7.93	*t*(148)=1.48, *p*=.140
Quality of Life Scale	6.07	1.88	5.75	2.00	*t*(148)=0.96, *p*=.340
	n	**%**	**n**	**%**	
Gender					
Female	87	84	38	81	Fisher's Exact *P*=.811
Male	16	16	9	19	
Education					
High School	19	18	8	17	Chi Square =2.76, df=2, p=.252
College	52	51	18	38	
Graduate School	32	31	21	45	
Relationship to Care Recipient	**n**	**%**	**n**	**%**	
Spouse or partner	56	54	21	45	Chi Square =1.51, df=2, p=.470
Child	36	35	20	42	
Other relative	11	11	6	13	
Ethnicity					
Hispanic/Latino	3	3	4	9	Fisher's Exact Probability Test p=.200
Other	100	97	43	91	
	n	**%**	**n**	**%**	

	Completers (N=103)		**Drop-Outs (N=47)[**]**		***t*, chi square or Fisher's exact**
Variable	**Mean**	**SD**	**Mean**	**SD**	
Race					
Caucasian	89	86	45	96	Fisher's Exact Probability Test p=.096
Other	14	14	2	4	
Care Recipient Diagnosis					
Alzheimer's Disease	70	68	30	64	Chi Square =0.25, df=2, p=.881
Vascular Dementia	10	10	5	11	
Other CNS Disorder	23	22	12	25	
Do you search Internet for information?					
Yes	100	97	46	98	Fisher's Exact Probability Test p=.628
No	3	3	1	2	
Have you done Online Training?					
Yes	45	44	19	40	Fisher's Exact Probability Test p=.423
No	58	56	28	60	
Do you watch online videos?					
Yes	86	83	42	89	Fisher's Exact Probability Test p=.458
No	17	17	5	11	

[**] Dropout rate = 31%

[a] Range of Services: 1 to 5 = 1 to 5 services (e.g. transportation, finances, shopping, respite, housekeeping or socialization); 5= personal care; 6 through 10 = personal care plus 1 to 6 other services.

[b] Revised Memory and Behavioral Problems Checklist (RMBPC)- Conditional Bother (If a particular memory or behavioral problem occurred, how much did it bother the participant.)

[c] Center for Epidemiological Studies - Depression Scale

[*] Missing values for participants on these variables - 3 on care recipient age; 2 on RMBPC

Table 2

Socio-demographic Characteristics, Caregiving Activities and Professional Services Used for Participant Completers Grouped According to Assignment to the iCare or the Information Comparison Condition.

	EOC** (N=57)		ICC** (N=46)		*t*, chi square or Fisher's exact
Variable	**Mean**	**SD**	**Mean**	**SD**	
Age of Caregiver	57.02	12.53	55.22	11.31	*t*(101)=0.76, *p*=.451
Age of Care Recipient (PWD) *	80.05	8.28	74.71	11.33	*t*(99)=2.74, *p*=.007
Services Caregiver provides [a]	7.70	2.21	7.00	2.51	*t*(101)=1.55, p=.130
Number Hours Care Per Week	63. 64	40.55	70.65	40.59	*t*(101)=0.87, p=.400
Number Services Used [b]	1.96	1.58	2.02	1.32	*t*(101)=0.20, p=.850
	n	**%**	**n**	**%**	
Gender					
Female	49	86	38	83	Fisher's Exact *P*=..786
Male	8	14	8	17	
Education					
High School	12	21	7	15	Chi Square =0.53, df=2, p=.527
College	26	46	26	57	
Graduate School	19	33	13	28	
Relationship to PWD					
Spouse or partner	29	51	26	56	Chi Sq.=0.63, df=3, p=.882[a]. Expected count <5 in 4 cells. [a] Collapsed last 4 cells into 2. Chi Sq.=.33, df=2, p>.80
Child	21	37	15	33	
Other relative	4	07	2	04	
Non Relative	3	05	3	07	
Ethnicity					
Hispanic/Latino	3	5	0	0	Fisher's Exact Probability Test p=.251
Other	54	95	46	100	
Race					
Native American	1	02	1	02	Chi Sq.=3.95, df=5, p=.556[a]. Expected count <5 for too many cells. [a] Collapsed into 2×2, Caucasian vs Other Chi Sq.=.525, df=1, p=.469
Asian American	3	05	2	05	

	EOC** **(N=57)**		**ICC**** **(N=46)**		***t*, chi square or Fisher's exact**
Variable	**Mean**	**SD**	**Mean**	**SD**	
Hawaiian/Pacific Islander	1	02	0	00	
African American	1	02	2	04	
Caucasian	48	84	41	89	
Other	3	05	0	00	
PWD Diagnosis					
Alzheimer's Disease	37	65	33	72	Chi Sq.=5.45, df=7, p=.605[a]. Expected count <5 *for 12* cells (75%). [a] Collapsed into 2×2, Alzheimer's vs Other Chi Sq.=.040, df=1, p=.842
Vascular Dementia	5	9	1	2	
Alzheimer's and Vascular	3	5	1	2	
Parkinson's Disease	1	2	1	2	
Lewy Body Dementia	2	3.5	2	4	
FrontoTemporal Dementia	0		2	4	
Unspecified Dementia	7	12	5	11	
Other CNS Disorders	2	3.5	1	2	

[a] Range of Services: 1 to 5 = 1 to 5 services (e.g. transportation, finances, shopping, respite, housekeeping or socialization); 5= personal care; 6 through 10 = personal care plus 1 to 6 other services.

[b] Type service: Support group, Clergy, Home Care, Case Mgr., Therapy, Medication, or Day Care

[**] EOC = Education Only Condition; ICC = iCare Condition

[*] Missing values for 2 participants on Age of Care Recipient

Table 3

Description of the iCare protocol

Topic Headings	Brief Content Description
1. About dementia	Overview of Alzheimer's Disease and related demenitas Basic facts and stages of dementia Course of illness and caregiving
2. Module 1. Dealing with stress	Strategies for dealing with stress Thoughts about stress Stress signals Challenging and replacing unhelpful thoughts Tips on challenging negative thoughts Using my thought record
3. Module 2 Learning how to relax	Rationale for using relaxation Types of relaxation techniques and discovering what works for you
4. Module 3 Pleasant Activities	Pleasant Activities for you and your loved one How do I do a pleasant activity? The pleasant activity plan Carrying out the plan and noting the effect Developing a pleasant activities plan for my loved one and me.
5. Module 4 Learning new communication skills	Aggression to submission; the communication continuum Practical tips you can use in talking to your loved one, your doctor, a family member about caregiving issues
6. Module 5 Managing difficult behaviors	Breaking down the problem: Trigger -Behavior - Response (TBR) Understanding and handling the problem using the TBR model How does this work with someone who has dementia Specific tips for different behaviors
7. Module 6 Healthy habits	What stressful times do to healthy habits Learning to monitor health behaviors Eating right, being active Charting a plan and learning how to follow it
8. Planning for the future	Anticipating the hurdles and developing a plan. Identifying national, state and local resources and how to use them

Table 4

Pre- Post-Intervention Means and SDs of Outcome Measures for Participants Grouped According to Treatment Condition.

Outcome Measure	**EOC[**]**	**(N = 57)**	**Pre- Post Paired *t* test**	**ICC[**]**	**(N = 46)**	**Pre- Post Paired *t* test**
	Mean	**SD**		**Mean**	**SD**	
PSS[1]						
Pre-	16.22	6.87	*t*(56) =0.231 p=.818	18.46	5.20	*t*(45) =3.18 p=.003
Post-	16.41	7.15		15.83	5.07	
RMBPC[2]						
Pre-	1.03	0.66	*t*(56) =1.36 p=.178	1.17	0.69	*t*(45) =3.640 p=.001
Post-	0.91	0.75		0.83	0.63	
CES-D[3]						
Pre-	14.10	7.82		16.71	7.95	
Post-	13.33	9.31		14.19	7.68	
PQoL[4]						
Pre-	6.25	1.90		5.85	1.84	
Post-	6.31	1.84		6.34	1.54	

[1] Perceived Stress Scale.

[2] Revised Memory and Behavior Problems Checklist - Conditional Bother - (Caregiving specific stress).

[3] Center for Epidemiology Studies-*Depression* Scale.

[4] Quality of Life.

[**] EOC = Education Only Condition; ICC = iCare Condition