Published in final edited form as:

J Gerontol Nurs. 2015 October ; 41(10): 18–24. doi:10.3928/00989134-20150804-61.

CARES® Dementia Care for Families™:

Effects of Online, Psychoeducational Training on Knowledge of Person-Centered Care and Satisfaction

Dr. Joseph E. Gaugler, PhD [Associate Professor and McKnight Presidential Fellow],

School of Nursing, Center on Aging, University of Minnesota-Twin Cities, Minneapolis

Mr. John V. Hobday, MA [Chief Executive Officer],

HealthCare Interactive, Inc., Minneapolis, Minnesota

Ms. Joyce C. Robbins, MS [Scientific Consultant], and

HealthCare Interactive, Inc., Minneapolis, Minnesota

Ms. Michelle P. Barclay, MS [Vice President]

HealthCare Interactive, Inc., Minneapolis, Minnesota

Abstract

Challenges to intervention use among family caregivers of individuals with dementia include availability and timing of delivery. The current study sought to determine whether an online, psychoeducational intervention for dementia family caregivers, CARES® Dementia Care for Families™ (CARES for Families), improved and enhanced dementia caregivers' knowledge of person-centered care approaches. Forty-one family members completed pre- and posttest surveys that assessed improvement in dementia care knowledge, and multiple close- and open-ended items examined how the CARES for Families online modules benefited users at posttest. A paired *t* test demonstrated a significant and considerable increase in dementia care knowledge among family caregivers ($p < 0.001$); caregivers also indicated that CARES for Families' content, flexibility, and use of actual family caregivers and individuals with dementia in video care vignettes were strengths. The findings suggest that CARES for Families can offer an efficient supplement to holistic dementia care that gerontological nurses provide.

In 2013, 5.3 million individuals with Alzheimer's disease and related dementias (ADRD) in the United States were cared for by 15.4 million family caregivers who provided 17.5 billion hours of unpaid help (Alzheimer's Association, 2014). Due to a large-scale need for family caregivers to acquire skills and strategies to effectively manage dementia symptoms, a range of psychoeducational interventions have been developed and tested (Adelman, Tmanova, Delgado, Dion, & Lachs, 2014).

Psychoeducational interventions are "structured programs that provide information about the disease, resources and services, and about how to expand skills to effectively respond to symptoms of the disease (e.g., cognitive impairment, behavioral symptoms and care-related

needs)” (Alzheimer’s Association, 2014, Table 7). Content is delivered via lecture, discussion, or written handouts. Psychoeducational interventions are often led by professional experts, such as nurses in memory clinics or other specialty settings, who provide skills training related to the management of dementia.

Although psychoeducational interventions have shown promise in reducing stress and improving the coping skills of family caregivers of individuals with ADRD (Hepburn, Lewis, Tornatore, Sherman, & Bremer, 2007; Judge, Yarry, Looman, & Bass, 2013), there are often many barriers to accessing such interventions. For example, a lack of local availability or professional expertise, transportation and scheduling issues, or unawareness about the existence of such programs contribute to low use on the part of dementia caregivers (Czaja, Loewenstein, Schulz, Nair, & Perdomo, 2013).

One approach to overcoming the barriers to accessing psychoeducational services for ADRD caregivers is the use of portable, online delivery platforms. Online delivery of psychoeducational content can be done asynchronously, thus eliminating the need to schedule or travel to receive structured skills-training modules. In addition to smaller pilot studies of online psychoeducational interventions for dementia caregivers (Lai et al., 2013), larger evaluations have been conducted (Boots, de Vugt, van Knippenberg Kempen, & Verhey, 2014; Czaja et al., 2013; Hayden, Glynn, Hahn, Randall, & Randolph, 2012; Kwok et al., 2014; Lewis, Hobday, & Hepburn, 2010). Results suggest that ADRD caregivers who receive these interventions online or via other technology platforms indicate decreases in emotional distress, increased social support, and satisfaction with the convenience of online access of clinical content, although Internet connection quality and time constraints are potential limitations.

To contribute to and expand on the growing number of evaluations (both formative and outcomes based) of technology-enhanced ADRD caregiver interventions, the current study sought to determine whether an online intervention for ADRD caregivers (CARES[®] Dementia Care for Families[™] [CARES for Families]) improved their knowledge of dementia care and enhanced their care situations. The primary objective of CARES for Families is to offer family caregivers education about the skills and tools to provide person-centered dementia care—care that “supports the rights, values, and beliefs of the individual; involves them and provides unconditional positive regard; enters their world and assumes that there is meaning in all behaviour, even if it is difficult to interpret; maximizes each person’s potential; and shares decision making” (Edvardsson, Winblad, & Sandman, 2008, Panel 1). To achieve this type of care, CARES for Families incorporates and instructs families in the practical and easy-to-learn CARES Approach (C—connect with the person, A—assess behavior, R—respond appropriately, E—evaluate what works, and S—share with others) (Hobday, Savik, Smith, & Gaugler, 2010). The CARES for Families program also includes home-based care interventions portrayed through a variety of textual, audio, and visual resources; passive and active modes; interviews in streaming video; and resources for interactive feedback and interpersonal follow up. For these reasons, CARES for Families could act as an efficient and synergistic supplement to the ongoing clinical care that nurse professionals and other educators provide to individuals with dementia.

METHOD

Procedure

Formative Development of CARES for Families—A 14-person national expert panel comprising clinical and scientific experts in family caregiving as well as family caregivers convened to identify content relevant for the CARES for Families online training modules. Initial development of the online interface also occurred. In addition to the feedback solicited from the expert panel, core resources were used to inform the textual, video, audio, and graphic content in each module (Alzheimer's Association, 2009; Mittelman & Epstein, 2003; Mittelman, Epstein, & Pierzchala, 2003; Reed & Tilly, 2008). Following the development of content outlines, video and audio scripting were conducted for the various CARES for Families modules. A series of prototypes were developed and evaluated by the 14-person national expert consulting team. In addition, a review of feedback on the feasibility of CARES for Families by 20 family caregivers was taken into consideration.

Following the refinement of the beta CARES for Families online modules, a pre-/posttest design was used to evaluate empirical change in dementia care knowledge and examine descriptive qualitative and quantitative data on the positive and negative aspects of CARES for Families. Each caregiver enrolled in the pre-/posttest evaluation was provided access to the finalized version of the CARES for Families online training program. Prior to accessing the program, the caregiver completed an online consent form, demographic form, and pretest inventory. The average time between the pre- and posttest surveys was 17.05 days ($SD = 19.65$ days). The University of Minnesota Institutional Review Board provided human subjects research approval.

Sample

Caregivers were recruited from a number of sources, including the Alzheimer's Association's Trial Match service, the Minnesota–North Dakota Alzheimer's Association regional office, and community outreach to organizations that have collaborated with Health Care Interactive, Inc. in the past. Family members of an individual with ADRD still living at home or in an assisted living facility and who had access to a high-speed Internet connection were included. One-hundred twenty-three participants were initially enrolled who met the inclusion criteria, and 41 of these family caregivers completed the pre-/posttest evaluation of CARES for Families.

CARES for Families Psychoeducational Modules

The CARES for Families program included extensive video footage. Actual family caregivers, professionals, national experts, and individuals with ADRD (i.e., no actors) were used in all video segments with no scripting. Videos comprise care vignettes, such as family members helping an individual with ADRD address mobility issues, family members describing difficulties in their lives and successful solutions, and family members using the CARES Approach to help manage behavioral issues in the individual with ADRD. In addition, videos include interviews with national expert project consultants and community health professionals offering advice to users. This format brings “experts into the living room” for family caregivers who used CARES for Families. CARES for Families modules

included three 1-hour modules covering the following topics: (a) *Understanding Memory Loss* (defines and explores the causes of ADRD, defines cognitive decline related to dementia, and explores the implications for performance of activities of daily living; seven screens, 17 videos, 60 minutes); (b) *Living With Dementia* (reviews strategies to help individuals with dementia function independently and safely and identifies tools for family caregiver stress management; 18 screens, four videos, 60 minutes); and (c) *Using the CARES Approach* (presents the CARES Approach for users to apply in their own family caregiving situations; 11 screens, 18 videos, 60 minutes).

Data Collection

Demographic/Background Data—Caregiver gender, age, race and ethnicity, marital status, duration of care, highest level of education received, relationship to the individual with dementia, and computer literacy (i.e., whether the caregiver has used a computer before, owns a computer, has taken a training class on a computer) were included as descriptive characteristics.

Dementia Care Knowledge—A 20-item, multiple-choice and true/false measure was developed to test family caregivers' knowledge before and after use of CARES for Families. As summarized above, the content validity of the measure was established based on suggestions by the 14-person national expert team and was refined following multiple iterations to result in a measure that was brief yet also included multiple domains of knowledge regarding person-centered ADRD symptom management. The number of correct responses was summed at pre- and posttest. The measure is included in Table A (available in the online version of this article). The full measure demonstrated moderate reliability at posttest (Cronbach's $\alpha = 0.63$).

Satisfaction Items—Thirteen Likert scale items were administered at posttest that examined various aspects of satisfaction with CARES for Families. A summary of the measure, as well as associated results, is included in the Table.

Open-Ended Items—Questionnaires included four open-ended items that further explored the benefits and challenges of using the CARES for Families online psychoeducational program. Items included: "What did you like best about this training program?"; "What did you like least about this training program?"; "How is this training program useful to you in caring for your family member with dementia?"; and "If you were recommending this online training program to someone else, what would you tell them about it?"

DATA ANALYSIS

A paired *t* test was used to determine whether the summed correct score on the dementia care knowledge measure at posttest was significantly different from pretest (i.e., $p < 0.05$). Frequencies of satisfaction items were also analyzed to determine which aspects of the CARES for Families training program family caregivers deemed most beneficial at posttest. Respondent data provided on the four open-ended items were examined and content was

analyzed to identify challenges and strengths of CARES for Families related to the provision of family dementia care.

RESULTS

Sample Characteristics

Most study participants were women ($n = 37$, 90.2%). Participants were either White ($n = 37$, 90.2%) or Asian ($n = 4$, 9.8%). Two of the White participants were Hispanic/Latino (4.9%). More than 70% of the sample was married ($n = 29$); six were divorced (14.6%) and six were never married (14.6%). More than three quarters of the sample had a Bachelor's degree or greater education ($n = 31$). Average caregiver age was 58.02 ($SD = 10.94$ years, range = 39 to 89 years). Users had provided care to their relatives with ADRD for an average of more than 3 years (mean = 38.24 months, $SD = 34.96$ months, range = 6 to 156 months). All but one participant had used a computer before, and more than 70% of the sample had taken a training class by computer previously ($n = 30$).

Pre-/Posttest Dementia Care Knowledge

Among the 41 caregivers who completed the pre- and posttest dementia care knowledge scale, 81.5% ($n = 33$) indicated a gain in dementia care knowledge, 12.2% ($n = 5$) showed no change, and 7.3% ($n = 3$) demonstrated a decrease in knowledge. At pretest, dementia caregivers on average attained 10.17 ($SD = 2.17$) correct responses on the knowledge measure; at posttest, respondents attained 13.07 ($SD = 2.82$) correct responses ($t = 6.60$, $df = 40$, $p < 0.001$). As shown in Table A, greater percentages of respondents indicated correct responses at posttest on 19 of the 20 knowledge items than at pretest.

Satisfaction Items

The Table provides item-level information on family caregivers' satisfaction with the various facets of CARES for Families. More than 90% of family caregivers *strongly agreed* or *agreed* that CARES for Families compared favorably to classroom or standard text learning; that the online information was clear, easy to understand, and improved confidence in dementia care; and that users would recommend CARES for Families to other family and professional caregivers. More than 80% of caregivers also *agreed* or *strongly agreed* that the graphic, audio, and textual aspects of CARES for Families were useful.

Open-Ended Item Analysis

Caregivers indicated a number of positive aspects of CARES for Families in the open-ended items, and these responses helped explain why the online modules were effective in improving knowledge related to the provision of person-centered dementia care. Aspects deemed particularly positive included the comprehensive content, the use of real individuals with dementia and their caregivers in video care vignettes, and the flexibility of online delivery:

- I found all of this training very helpful and well thought out...I have been caring for my grandmother full-time in my home for the past 9 months...this training would have been very helpful if it were available to us at the start of our journey.

I did hours of Internet [sic] research to gather the many tips and strategies presented in the training, and they work.

- I really liked the videos that showed the progression of the disease in the early, middle, and late stages of the disease. For example: the making coffee and taking a bath examples. I also liked the driving example, too, in relation to the different parts of the brain and how they are affected. As a caregiver, it really helps me get an idea of how my family member is going to progress.

Family caregivers also indicated several deficiencies in CARES for Families, with comments including:

- I didn't like the ending. I found it very sad to be left with the vision of the dear man peeling bananas. You could have chosen something a bit more uplifting...I felt that they had all come to terms and made the best of it—and so can we!!!
- A few technical and display issues. Video segments were displayed smaller than text window...had to go into settings to increase video screen size. Audio was cut short on several of the slides.

When considering how the CARES for Families program could potentially influence the actual provision of care, family caregivers noted the many tools, resources, and educational aspects of the online modules:

- I consider myself an even-keeled, compassionate person. Yes, sometimes I get frustrated and have to leave the room to keep from saying something I might later regret. This training program showed me ANOTHER WAY, and I didn't even know there was one.
- Gave more insight as to how both family members and those with memory loss are dealing with it. Some different ways to help family members with memory loss. Will go back to review various parts of videos just to gain more insight to help family member with memory loss in order to help them in their everyday life.
- ...the examples and the stories of families who live with Alzheimers [sic] were very informative and gave me comfort that I, too, can do this.

As noted in the close-ended satisfaction items, family caregivers were highly likely to recommend CARES for Families to others, and an open-ended item allowed users of the modules to explain how and why they would do so:

- I would tell them (and already have told several people from my Alzheimer's [sic] support group) that this program gives real-life instances of issues that arise and suggestions for working through them. The program also gives the perspective of those living with the disease—something I am clueless about. I feel empowered because of the information I've been given. I'd like to continue to revisit this website for reviewal [sic] of the training information.
- I would say that this is a great program for the journey involved in an Alzheimer's diagnosis, and that this is useful throughout the progression for all

stages and for different roles involved in the diagnosis. If this program were available for purchase on DVD, I would consider buying and sharing with family members to educate them and help them to help me care for my mother.

DISCUSSION

Caregivers who used CARES for Families showed considerable gains in knowledge of strategies to provide person-centered dementia care. On average, caregivers increased their positive answers on the 20-item knowledge scale by 3 points from pre- to posttest, and more than 80% of users demonstrated gains in knowledge. As the need for education, tools, and strategies is often a critical concern for family caregivers of individuals with ADRD, the potential of CARES for Families to deliver such content to users is an important finding. Given the online format of CARES for Families, the findings also imply that the delivery of this content can be done in a flexible manner, and that rural or other underserved dementia caregivers could potentially benefit.

Several components of the online psychoeducational modules appeared to drive the positive effects on dementia care knowledge and other domains. Almost all caregivers indicated that CARES for Families was interactive, engaging, and easy to understand. Following use of the online modules, family caregivers indicated greater confidence and mastery in their caregiving skills and communication, and were almost universal in their recommendations of the program to other family caregivers or professionals. CARES for Families appeared to stimulate new caregiving ideas and approaches that family members had not considered prior to use and the flexibility of the online delivery approach (e.g., fitting the viewings into a family caregiver's busy schedule, allowance of re-review of content as needed) were additional aspects that were well received.

Following use of the online modules, family caregivers indicated greater confidence and mastery in their caregiving skills and communication.

The open-ended, post-CARES for Families data suggest several mechanisms of benefit in addition to challenges to consider when refining online delivery of psychoeducational content for ADRD family caregivers. Particularly relevant to users was the focus on stages of ADRD and what to expect/anticipate as the disease progresses. In addition to the quality of the care strategies and resources included (which "worked" when applied to individual care situations), other strengths of the CARES for Families online delivery included: (a) the opportunity it provided for family caregivers to review applicable content as the need arose; (b) the various strategies and alternatives reviewed to overcome dementia care obstacles; and (c) the validation that the online content provided. Several caregivers noted that they had used trial and error to resolve issues and care challenges in the past, and the CARES for Families video care vignettes and content validated their chosen solutions (one user had wished that she/he had access to CARES for Families earlier to identify helpful care strategies and solutions more efficiently). Of particular importance, and one that perhaps sets CARES for Families apart from other online intervention modalities, is that users could emotionally relate to the video care vignettes of actual family caregivers, individuals with ADRD, and their personal milestones when adapting to and resolving challenges related to dementia.

LIMITATIONS

Although multiple mechanisms of the program's benefit are demonstrated, areas of improvement were also identified in the current study. One user reacted negatively to the ending of one of the modules due to its authentic, real-life presentation. More common critiques were the length and tendency of the content to become somewhat repetitive throughout the duration of CARES for Families use, as well as various technical issues (e.g., long video and audio load times due to the quality of users' Internet connections [Hayden et al., 2012]).

In addition to the challenges raised in the open-ended responses, an important limitation of the current study is that the pre-/posttest evaluation did not include a control group. Although the dementia care knowledge scale used as the principal empirical outcome was developed for the current study via a robust iterative process, the full measurement validity and reliability of this measure was not established prior to inclusion. The small sample may have limited statistical power and reduced generalizability, and information was not available to determine why of the 123 participants enrolled, only 41 completed the pre- and posttest evaluation of CARES for Families. Finally, CARES for Families did not address whether use of the online psychoeducational modules led to changes in how actual person-centered care was provided to individuals with ADRD or whether this use of the modules resulted in actual improvements in other key caregiving outcomes.

CONCLUSION

Psychoeducational interventions have demonstrated particular promise in providing dementia caregivers with the skills and strategies to manage the many challenging symptoms of a relative's ADRD (Selwood, Johnston, Katona, Lyketsos, & Livingston, 2007; Sörensen, Pinquart, & Duberstein, 2002; Thompson, Herrmann, Rapoport, & Lanctôt, 2007). This initial evaluation of CARES for Families suggests the promise of delivering dementia caregiver psychoeducation via an interactive, graphic, and video-based set of modules, which can overcome the barriers of geographic distance and availability. In this regard, the implementation of CARES for Families or similar online modules could have significant clinical implications. When older individuals with dementia receive routine clinical care, the focus of these visits often revolves around medical issues or health concerns of the patient with memory loss (e.g., medication management), and the time necessary to effectively address family caregiver concerns is scant. CARES for Families, or similarly intensive online psychoeducational interventions, could augment routine memory loss care. In addition, it would be helpful for families to have preliminary knowledge of ADRD and ADRD care to optimize sessions with clinicians; for example, families could view CARES for Families modules to enhance their feelings of competence and self-efficacy prior to initial or ongoing clinic visits, thus resulting in more productive clinical contacts. With the increasing pressures of cost and time making robust, in-person dementia management challenging, providing online training such as CARES for Families could help achieve more optimal, family-centered dementia care.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

Acknowledgments

Dr. Gaugler and Ms. Robbins are paid scientific consultants and Mr. Hobday and Ms. Barclay are employed by HealthCare Interactive, Inc. This research was supported by a grant from the National Institute on Aging to HealthCare Interactive, Inc. (1 R43 AG033419-01; J.V. Hobday, Principal Investigator). The authors thank Sarah Sommers for her contributions to this research and Kathy Confer for her assistance with this manuscript.

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TABLE

TAGE OF DEMENTIA FAMILY CAREGIVERS WHO *STRONGLY AGREED* OR *AGREED* ON CARES[®]
 DEMENTIA CARE FOR FAMILIES[™] SATISFACTION ITEMS

Item	Strongly Agreed/Agreed (%)
1. Was an interesting way to learn compared to learning in a classroom, or by reading.	92.7
2. The information presented in this training program was easy to understand and follow.	97.5
3. I am more confident about my skills in helping and caring for my family member with dementia after completing this training program.	90.3
4. I would recommend this course to other families.	95.1
5. I would recommend this course to professional caregivers (home health aides, nursing assistants, etc.).	95.2
6. The videos gave me new ideas on how to interact with someone with dementia.	87.8
7. As I completed the training program, it was important to be able to go back and review sections of the program as often as I wanted.	87.8
8. The information provided in the training program will help me better communicate with my other family members, professional caregivers, and my family member with dementia.	87.8
9. I have a better understanding of the changes in thinking that are associated with dementia after completing the training program.	85.4
10. I am more confident and comfortable in communicating with someone with dementia after completing this training program.	85.4
11. It was easy for me to fit the training program into my schedule.	80.5
12. I preferred learning with the Internet-based training program as opposed to sitting in a classroom.	80.5
13. The graphics, sounds, and video in this presentation made the training more interesting than other training programs I have participated in.	78