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Internet-Based Program for Dementia Caregivers

Marsha L. Lewis, PhD, RN[1], John V. Hobday, MA[2], and Kenneth W. Hepburn, PhD[1]

Abstract

The overall goal of the Internet-Based Savvy Caregiver (IBSC) program was to develop and bring to market an Internet-based psycho-educational program designed to provide dementia caregivers the knowledge, skills, and outlook they need to undertake and succeed in the caregiving role they have assumed. The IBSC program's concept is based on a face-to-face caregiver-training program and curriculum, the previously validated Savvy Caregiver Program (SCP). The project used an iterative design with expert and consumer input to develop the initial prototype. Forty-seven participants completed the IBSC program and follow-up questionnaire. Results of the formative evaluation showed that participants found the program educational, convenient, useful, and interesting. Participants endorsed feeling more confident in caregiving skills and communication with their family members. The evidence points to the feasibility of an Internet-based program to strengthen family caregivers' confidence in caring for persons with dementia.

Keywords

dementia, family caregiver, Internet-based training, caregiver training, savvy caregiver

The number of Americans afflicted with dementing diseases is estimated at 5.3 million, with family caregivers providing most of the care. As life expectancy continues to rise and baby boomers age, by 2030 the number of persons with dementia of age 65 and older is estimated to reach 7.7 million. The Alzheimer's Association estimates that almost 10.9 million Americans serve in the role of family caregiver.[1] These caregivers provide most of the community-based care dementia patients receive, typically over extended periods of time at a well-documented cost to themselves. Viewed from multiple perspectives—physical and psychological well-being, immune function, economic condition, or family cohesion—those who provide care to a demented relative experience greater global distress than those who do not.[2] Issues of managing day-to-day living—handling unpredictable behavior and accomplishing the activities of daily living—loom largest in eroding caregiver capacity to continue care and lead most substantially to institutionalization.

Interventions, including psychoeducation programs, have been shown to be an effective means of equipping dementia caregivers for the work they do and of ameliorating the distress they experience as caregivers.[3-12] Disparities exist in distributing the benefits of such programs. Access to psychoeducation—as to other services—is problematic; it may be more problematic for rural caregivers or those in ethnic minority groups.[13-16] The burden of caring for a family member with dementia constitutes another barrier, in that caregivers find it difficult to leave their family member to attend in-person sessions.

In recent years, interactive Internet-based strategies to provide training to patients with a variety of acute and chronic diseases—and to their family caregivers—have been developed and shown to be effective. A number of studies have demonstrated that various distance-delivery techniques such as touch screen computers and interactive Internet programs are acceptable and effective in a variety of conditions, most of which involve elderly patients and their family caregivers.[17-29]

The Internet-Based Savvy Caregiver Program (IBSCP) merged the successful evidence-based psychoeducational intervention, the Savvy Caregiver Program (SCP),[7,8] with the access and interactivity afforded by the Internet to make available a beneficial service to a vitally important cadre of people, family dementia caregivers. The objective of the project was to translate and disseminate components of the SCP into an Internet-based psychoeducational program designed to provide persons caring for relatives who have dementing disorders the knowledge, skills, and outlook they need to undertake and succeed in the caregiving role they have assumed. The SCP, an Alzheimer's Association-supported project, developed a transportable dementia caregiver program based on the successful *Partners*

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[1] Nell Hodgson Woodruff School of Nursing, Atlanta, GA, USA
[2] HealthCare Interactive Inc., Minneapolis, MN, USA

Corresponding Author:
Marsha L. Lewis, 1520 Clifton Rd, Atlanta, GA 30322, USA
Email: marsha.lewis@emory.edu

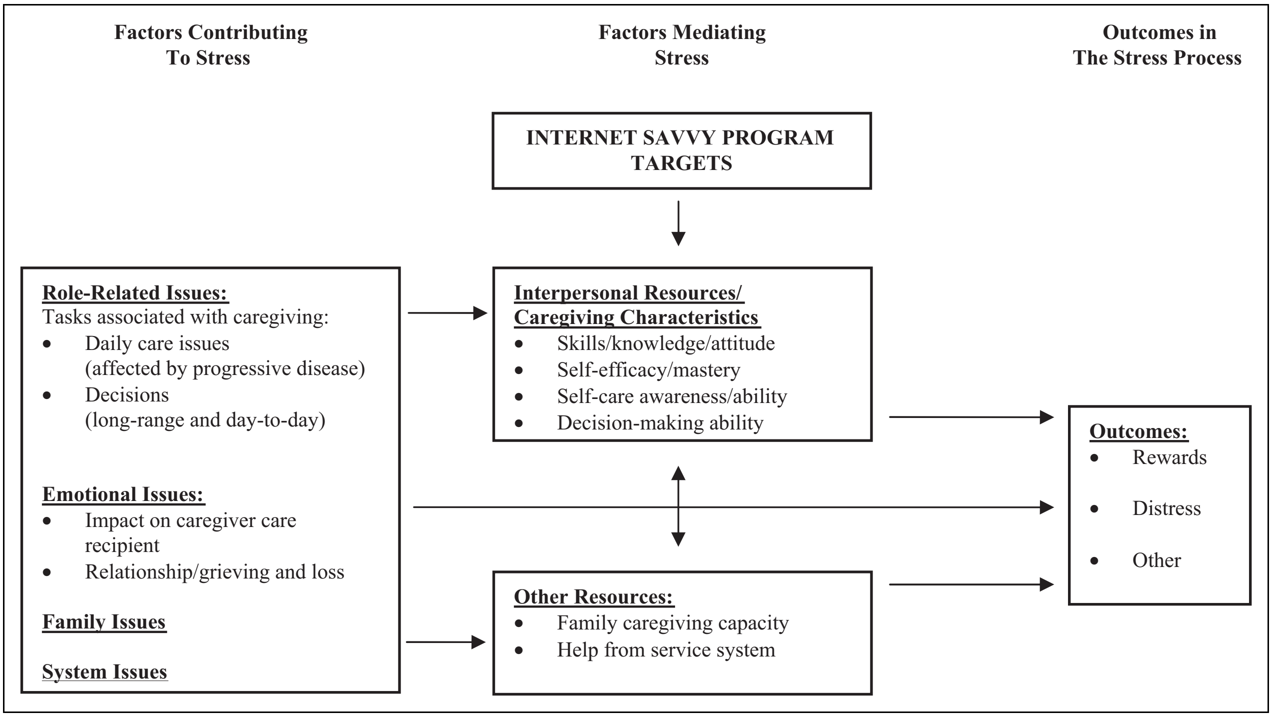

Figure 1. Stress and coping model.

in Caregiving intervention.[6] The SCP is able to be delivered by a variety of facilitators operating at distant sites.[8,30] The SCP is currently offered in a series of multihour, face-to-face small-group sessions extending over a 5- to 6-week period. Each session includes a number of topics and the sequence is designed to develop caregiving skills, knowledge, and outlook. In all, there are currently 18 topics covered in the program. Different topics promote different learning objectives. Some focus on knowledge acquisition, such as acquiring information about diseases that produce the kind of condition for which caregiving is required. Others concentrate on development of caregiving skills (eg, how to deflect paranoid ideation or how to deal with factually untrue statements made by a person with dementia). Still other parts of SCP are concerned with strengthening the learner's attitude about or outlook on caregiving (eg, how to appreciate the powerful impact on the person of dementia-produced confusion—and the strong and unpredictable reactions it can produce). As a whole, the program is aimed at developing or sharpening caregiving strategies and promoting an outlook on caregiving that enables the caregiver to engage in processes of assessment, planning, and evaluation.

The stress and coping model has been used as the theoretical framework for the SCP.[31,32] As portrayed in Figure 1, this model postulates that the positive and negative outcomes of the caregiving stress situation can be mediated by several factors, but particularly by the strengthening of the personal resources of the caregiver. Central to these personal resources are the caregiver's appraisals both of the situation itself and of his or her ability to manage it. Through its emphasis on the practice of newly acquired skills and strategies (undertaken in the context of newly acquired knowledge) and on the modeling of successful skills by others, psychoeducation seeks to promote the learner's sense of mastery and self-efficacy. In effect, it seeks to strengthen the caregiver's appraisal of his or her capacity to successfully provide care within the context of the stress situation. Part of this strengthening centers on the process of role acquisition and the shift in outlook that takes place as this occurs. The Internet-based format for the SCP acts as a contextual support to strengthen the interpersonal resources of the family caregiver. The Internet is an easily accessible means to influence caregiving resources because it provides content and skill development while addressing barriers such as the inability to leave the care recipient to attend a program.

This phase I NIH-funded project pursued 3 aims: (1) produce, through a validated instructional-design process, a new and unique design document and script appropriate for the interactive, Web-based delivery of 4 of the 18 manual-based SCP core modules; (2) develop a prototype version of the interactive IBSC program shell that includes the 4 core instructional content modules; and (3) establish the feasibility and acceptability of the program shell and initial content modules through a formative evaluation process with family caregivers.

Method

Design

Content development of the 4 modules selected from the SCP moved forward in an iterative manner. These modules were chosen because the researchers believed they could serve as a stand-alone program for the initial product. The 4 modules are (1) the effects of dementia on thinking; (2) taking charge and letting go; (3) providing practical help; and (4) managing daily care and difficult behavior. For example, the effects of dementia on thinking describes what happens to thought processes when dementia sets in and illustrates what the losses in 8 areas of cognition mean for caregiving. The Internet provides an excellent medium for demonstrating, in a dynamic, visual way, how these losses are manifest in the person with dementia. Both the content of the conversation and the nonverbal behavior of the person with dementia can be used to enhance the participant's understanding of how dementia affects cognition. We enlisted persons with dementia and their family caregivers in the community who were willing to allow us to videotape some of their interactions. We videotaped family caregivers describing situations that illustrate the concepts. Content also includes written descriptions of the effects of dementia in these areas of cognition, examples of typical caregiver responses and savvy responses that take the cognitive loss into account, as well as strategies for caregivers to use. Caregivers can think about their own situations, identify examples of cognitive losses they have observed in their family member, and begin to identify strategies that might work for their situation. An advisory board that included experts in dementia, caregiving, and instructional and software design provided initial guidance on how best to present this content, meet the needs of family caregivers, and find the best fit of the content for an Internet-based program.

Each of the storyboard documents were between 30 and 50 pages in length, developed in Microsoft Word, and included all written text to be included in the module, representations of all interactive features of each screen, description of each video clip to be produced, and an explanation of online functionality for each screen (eg, what occurs when a user clicks on a certain button, graphic, or interaction).

Video footage was added to represent how the face-to-face program functioned, as well as to gather stories from family caregivers to use in the modules. One of the advisory group members who has facilitated a large number of SCP sessions agreed to convene a 4-session group with volunteers who signed agreements to be videotaped for the program. Footage was then used within the Internet program to highlight and clarify content and bring some of the milieu of a face-to-face session to the caregiver sitting at the computer

Advisory board members reviewed the storyboards for quality, cultural sensitivity, accuracy, consistency, reading level, and the more practical aspects of distribution and marketing of the program. Two family caregivers agreed to review the storyboards and provided the team with extensive notes and suggestions. These were incorporated, along with advisory board feedback into the final storyboards.

Development

The phase I prototype was developed as a browser-based computer program using the Adobe Flash programming environment. The program is accessible from any Internet-connected computer on either Macintosh or PC platforms. The program requires a Web browser (such as Internet Explorer or Netscape) and a Flash plug-in. If a user does not have the plug-in, the program prompts them to download it for free.

Formative Evaluation

After receiving approval by Emory University Institutional Review Board, we recruited a diverse set of family caregivers with the assistance of the national office of the Alzheimer's Association, Minnesota/Dakota, Colorado, and Georgia Alzheimer's Association chapters, and advisory board members. Informed consent was given by clicking a button on the electronic consent form that read, "I Agree." Over a 4-month period, 63 participants completed the consent form and provided demographic information online. They were sent the URL to access the program and asked to complete the program and the follow-up questionnaire. The caregivers were offered $50 for completing the IBSC program and the online follow-up questionnaire. The questionnaire included Likert-type items about usability, clarity, amount of information presented, and comfort with format, as well as questions related to the effect of the program on caregiver skills, strategies, and knowledge. Open-ended questions asked about strengths and weaknesses of the program, length of time to complete the program, usefulness, suggestions for improvement, and what the participant would tell others about the program.

Results

Sample Characteristics

A total of 47 participants completed both the program and follow-up questionnaire for a 74% response rate. There were no significant differences found between those who completed the study and those who did not. The mean age of the participants was 55 (SD = 9) with a range from 32 to 87 years. The sample was predominantly Caucasian (85%), female (85%), and educated, with 65% college graduates. Participants came from 10 states with the majority coming from Colorado and Georgia, followed by North Carolina and Minnesota, with 19% living in rural areas. The participants were caregivers for their family members for an average of 3.8 years (SD = 3.9 years) with a range from <1 to 21 years.

Quantitative analysis. Participants responded to Likert scale evaluation questions (where 1 = *Strongly Disagree* and 5 = *Strongly Agree*). Table 1 presents the percentage of responses in each category. The questions reflect both a caregiving subscale and a program subscale. More than 90% of participants scored agree or strongly agree on 4 of 5 questions on the caregiving subscale. The program subscale yielded scores of agree or strongly agree ranging from 76.6% to 91.5%.

The data were analyzed to see whether there were any significant relationships between demographic data and responses. For the most part, there were no significant relationships. We did find a mild correlation between age and

Table 1. Program Questionnaire–Percentage of Responses on a Scale From 1-5 (Strongly Disagree to Strongly Agree)

Caregiver subscale (N = 47)	1	2	3	4	5
1. I am more confident about my skills in caring for my family member after completing this training program.	0	0	6.4	55.3	38.3
2. The program gave me new ideas on how to care for someone with memory loss or dementia.	0	2.1	2.1	46.8	48.9
3. I have a better understanding of the changes in thinking that are associated with dementia after completing the training program.	0	4.3	19.1	36.2	40.4
4. I am more confident and comfortable in communicating with my loved one with dementia since completing this training program.	0	0	0	46.8	53.2
5. I feel more confident and comfortable in caring for my loved one than I did before I completed this training program.	2.1	0	10.6	53.2	34.0
Program subscale (N = 47)					
6. The Internet Savvy Caregiver program contained the right amount of information	0	0	4.3	59.5	36.2
7. The directions for using the program were clear.	0	4.3	12.8	55.3	27.6
8. The program held my interest.	0	10.6	6.4	51.1	31.9
9. I enjoyed learning with this Internet-based training program as opposed to attending a live class.	2.1	2.1	4.3	61.7	29.8

the caregiving subscale: as age increases the caregiving scale decreases (Pearson $R = -.297$, n = 47, P value = .042). There was a difference between Caucasian and non-Caucasian (primarily African American and Asian) participants for the total score and for the program subscale, where non-Caucasian participants had significantly higher scores on the total scale (Caucasians, n = 39 mean = 37.3 [SD = 3.8], non-Caucasians, n = 7 mean = 41.9 [SD = 2.5], t statistic = 2.996, df = 44, P value = .004) and program subscale (Caucasians, n = 39 mean = 15.9 [SD = 2.2], non-Caucasians, n = 7 mean = 18.7 [SD = 0.95], t statistic = 3.243, df = 44, P value = .002). (NOTE: One participant's race was not available which is why there are only 46 participants included for the t tests presented in the preceding paragraphs.)

Qualitative analysis. Participants typed in responses to open-ended questions. Therefore, there were written data to review. The qualitative data were analyzed using the methods of constant comparative analysis. One member of the study team (M.L.L.) read through responses to individual questions and assigned codes to elements of meaning discerned in the text. These codes were later combined into sets of themes associated with each of the evaluation questions. Independently and without prior reference to the developed coding scheme and themes, a second member of the study team (K.W.H.) read through the responses to individual questions and compiled impressions of codes and themes for each question. This second reading confirmed the themes and did not result in the development of additional or competing themes.

The identified themes in the qualitative data are described below. For the question, "What did you like best about this training program?" the responses fell into 4 main categories: (1) information and caregiving strategies; (2) videoclips of professionals, caregivers, and persons with dementia; (3) convenience of the Internet program; and (4) presentation of the program. In all, 30% commented that the information presented and the strategies identified were useful. "Good information, I found myself surprised at being able to relate to a lot of it." Respondents identified the video examples as interesting. "Person with dementia was very interesting and I felt like I could connect with them." The convenience of viewing the program at home and in their own time was considered useful, by 30% of the participants, "I enjoyed having more control over when, where, how long, and how much I worked." In regard to presentation, the participants appreciated the tone of the program (no talking up or down), the way it was broken into sections, and interactive aspects. One participant summed up a number of these themes, "Good information attractively presented by a variety of speakers, both caregivers and experts."

When asked, "what did you like least about this training program?" 10 respondents commented that they could not find anything they did not like. The remaining responses included (1) technical difficulties (editing needs), (2) repetition of information, (3) the length of the program, and (4) for a small number, not being able to ask questions and interact with others as they worked through the program. Participants expressed concerns over spelling errors and navigation difficulties. "There was no way to mark where I left off each time, so I had to start over each time I returned to the program." Some described parts as overwhelming and that it seemed a little too long. "The length, I wished I could have watched it in one sitting." Eight participants commented on repetition of some of the material. Although this was intentional at times to reinforce content, some participants found it troublesome. "Same thing repeated over again in each module." The lack of contact with others was a concern for two respondents. One participant wrote, "I don't have the option of sharing, or interacting with others. The opportunity for questions related to my situation are not possible (although I was amazed at how often the training content did relate to things we are dealing with even in the early stages)."

When describing how the program was useful to them and what they would tell others about the program, 45% responded with learning strategies or techniques for dealing with the behaviors associated with dementia, followed by 12% identifying more knowledge and understanding the behaviors they are experiencing. One respondent summed up her view of the program thus, "It is a gentle reference vehicle to understanding Alzheimer's changes. It won't smack you in the face with the fear of what is coming but will prepare you for techniques to cope."

The suggestions that participants made to improve the training program reflected the answers to the question in the preceding sections. Besides suggestions for making it easier to navigate and suggestions for specific edits to the program, 3 participants did suggest an accompanying workbook for them to view something in print. (Note: users were able to print information from any screen they wished by clicking on a global "Print" button). Four commented that they completed the program over several days as it was a lot of information to take in during one session. Other comments included additional content that is in some of the other modules of the printed version of the Savvy Caregiver, such as information about medications and planning for the future decision making. Many wrote that they could not think of any suggestions.

Discussion

Aims 1 and 2 (produce Web-based delivery of modules from the SCP and develop a prototype version of the IBSC program shell) were accomplished through an iterative process that incorporated both expert and caregiver input. The prototype Internet-based Savvy Program was developed from an empirically tested caregiver intervention—the SCP.[8] The delivery of content electronically requires the innovative use of multimedia tools to enhance learning. The use of animation has been shown to aid in performance and improve learning.[33] Although the content from the SCP was the foundation for the IBSC program, we needed to create a very different educational design to make optimal use of the Internet-based format. We used an iterative process to develop the program, receiving feedback during the design phase from experts in dementia caregiving, and in instructional design, facilitators of the SCP, as well as veteran family caregivers, revising the storyboards and seeking further feedback.

The third aim (establish feasibility and acceptability) was achieved by participants' responses through quantitative data and written responses to questions. Participants endorsed the program's acceptability and usability, and through high ratings of caregiving confidence supported the feasibility of this type of program. The ratings on the caregiver subscale indicate preliminary demonstration that the program functioned effectively; it produced results predicted by the conceptual model—participants identified increased knowledge and understanding of dementia caregiving and reported an increase in self-efficacy. These results indicate that this type of format is acceptable and provides rationale for further development of the Internet-based program to include additional modules from the SCP.

All ratings were above 80% and most above 90% except the statement related to enjoying learning with this format as opposed to attending a live class (76.5% agreed or strongly agreed). Two participants commented about this in the open-ended responses, stating that they wanted to be able to ask questions and interact with others. This suggests an opportunity to refine the program, adding opportunities for interaction with other caregivers and professionals, perhaps in a chat room format.

The significant but mild correlation between age and the caregiving subscale needs further study. Older caregivers rated the items at a lower level. There was no literature found that addresses age and caregiving confidence. Exploration is required to better assess whether the delivery method for the content affected older caregivers differently. Did this difference exist prior to the intervention? Is there a correlation between age and caregiving confidence more generally?

Non-Caucasian participants scored higher on the program subscale than Caucasian participants. This finding is worth pursuing further to identify if this format is of particular value to a minority population. Given the disparities identified in the literature for non-Caucasian caregivers, the dissemination of information about caregiving through this medium could affect caregiving in this population. These results highlight one limitation of this study; we did not use a pre- and posttest design that may have helped answer questions about how useful the Internet program may be for different populations.

All of the participants have used computers and therefore, may be a more computer "savvy" population than other caregivers. The US Census Bureau reported that 58% of people 55 years or older had Internet use at home.[34] Thirty-eight percent of the participants in the study were 55 years or older. As the population ages, the number of older adults who are comfortable using the Internet will continue to increase. The participants in this study received $50.00 for completing the program and follow-up questionnaire. Although there is little written about the effects on the outcome of studies when financial incentives are provided research participants, it is important to note that incentives were given in this study. We chose the 4 modules from Savvy Caregiver because we believed they could serve as a stand-alone program that would benefit caregivers (and this was demonstrated by the participants responses to the caregiver subscale on the questionnaire); however, further development of other modules in the SCP will broaden the impact of this prototype. Results from this study demonstrate support to move forward with this Internet-based programming.

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