

# Effects of an Automated Telephone Support System on Caregiver Burden and Anxiety: Findings From the REACH for TLC Intervention Study

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**Purpose:** We determine the main outcome effects of a 12-month computer-mediated automated interactive voice response (IVR) intervention designed to assist family caregivers managing persons with disruptive behaviors related to Alzheimer's disease (AD). **Design and Methods:** We conducted a randomized controlled study of 100 caregivers, 51 in the usual care control group and 49 in the technology intervention group, who received yearlong access to an IVR-mediated system. The system provided caregiver stress monitoring and counseling information, personal voice-mail linkage to AD experts, a voice-mail telephone support group, and a distraction call for care recipients. We conducted analyses by using a repeated measures approach for longitudinal data and an intention-to-treat analytic approach. Outcomes included the caregiver's appraisal of the

bothersome nature of caregiving, anxiety, depression, and mastery at baseline, 6, 12, and 18 months. **Results:** There was a significant intervention effect as hypothesized for participants with lower mastery at baseline on all three outcomes: bother ( $p = .04$ ), anxiety ( $p = .01$ ), and depression ( $p = .007$ ). Additionally, wives exhibited a significant intervention effect in the reduction of the bothersome nature of caregiving ( $p = .02$ ). **Implications:** Wives who exhibited low mastery and high anxiety benefited the most from the automated telecare intervention. Findings suggest that, to optimize outcome effects, similar interventions should be tailored to match the users' characteristics and preferences.

**Key Words:** Caregiving, Dementia, Telecommunications, Interactive voice response systems

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The REACH for TLC study was supported by the National Institutes of Health (NIH) National Institute on Aging under Research Grant AG13255-01-06, which was awarded to D. Mahoney, PhD, Principal Investigator. This study was part of the NIH-sponsored Resources to Enhance Alzheimer's Caregiver Health (REACH) multisite collaborative project, 1995-2001.

We acknowledge the efforts of Sharon Tennstedt, PhD, Brooke Harrow, PhD, and Denis Cohen and staff at the New England Research Institutes, Watertown, MA, for managing the data collection. At Boston Medical Center we extend appreciation to Robert Friedman, MD, Medical Information Systems Unit, for oversight of the technology operations and IVR data collection; to Clare Wohlgenuth, RN, MS, the voice mail triage nurse; and to our panel of experts, Drs. S. Auerbach, M. Moss, and B. Silliman, B. Millen, and Ms. Licarta-Gher, RN, MS. We also thank Paul Raia, PhD, from the Massachusetts' Alzheimer's Association, and, from the Department of Veteran Affairs Medical Centers in Massachusetts, Ladislav Volicer, MD, PhD (Bedford), for his review of the IVR conversations and committee participation. We thank Kevin McIntyre, MD (West Roxbury), for sharing his insights from audiotaped family conversations with patients with Alzheimer's disease.

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Over the past decade, the integration of technology into our daily lives has pivotally affected the way we communicate with each other. Concerns have arisen, however, about those people lacking access to technology because they are more likely to be of lower socioeconomic status, members of racial or ethnic minorities, female, and older; these characteristics are already associated with underserved populations who are of historical concern to public policymakers (Irving, 1999). In 1994, the National Institute on Aging issued a request for proposals aimed at helping family caregivers of older people with Alzheimer's disease (AD), and it solicited innovative technological interventions in addition to traditional counseling and educational interventions (National Institute on Aging, 1994). In response, we developed an automated telecare application that integrated, to our knowledge for the first time, an interactive voice response (IVR)

system, rich with Alzheimer's information content, with a voice-mail telecommunications system for interactive messaging with peers and AD professionals. The IVR system was essentially a talking computer that spoke in response to signals received from a touch-tone telephone and asked the caller for a response either by voice or by pressing a number on the telephone keypad, whereas the voice-mail subsystem recorded and replayed users' conversations verbatim. We purposely designed the computer-mediated system to operate with the participants' ordinary telephones and telephone lines to facilitate access to technologically underserved populations, to minimize intervention costs, and, most importantly, to avoid altering the home environment of a person with cognitive impairment. In this paper we report the main outcome effects from a randomized trial to determine whether this system could reduce the stress associated with caring for a family member with Alzheimer's related disruptive behaviors.

### *Study Rationale and Hypotheses*

Caring for a relative with AD and related disorders involves substantial personal, social, and health costs (Hooker, Manoogian-O'Dell, Monahan, Frazier, & Shifren, 2000; Schulz, 2000). Recent evidence documents the greater demands faced by dementia caregivers when they are compared with caregivers of persons with other chronic diseases (Hooker, Monahan, Bowman, Frazier, & Shifren, 1998; Ory, Hoffman, Yee, Tennstedt, & Schulz, 1999). AD caregivers are reported as spending more time providing care than other caregivers and experiencing poorer health (Schulz & Beach, 1999), increased levels of burden (Vitaliano, Russo, Young, Becker, & Maiuro, 1991), anxiety, and depression (Gallant & Connell, 1997). Numerous studies confirm the association between dementia caregiving and both anxiety and depression (Kiecolt-Glaser & Glaser, 1999; Schulz, 2000). Disruptive behaviors, such as wandering and verbal assault common in middle-stage AD, are frequently reported by caregivers as the primary cause of their burdensome feelings (Gaugler, Davey, Pearlin, & Zarit, 2000; Teri, 1997). Disruptive behaviors vary greatly in their frequency, intensity, and consequences for all family members, contributing to the substantial variation in the level of burden reported by caregivers. Researchers have reported finding no positive linear relationship between care recipient impairment and appraisals of burden, and substantial individual differences in how well people adapt to caregiving demands are commonly reported (Schulz, 2000; Vitaliano et al., 1991).

The caregiving burden that people experience also is mediated by other factors, such as caregiving relationship and perceived mastery. Among the relationships, wives have constituted the majority of AD caregivers (Ory et al., 1999) and have ex-

perienced more physical and emotional stress than husbands (Horowitz, 1985; Rose-Rego, Strauss, & Smyth, 1998). Wives have provided more help and assistance with a wider range of tasks, frequently providing the necessary personal care activities that have been found to increase feelings of stress more than other caregiving tasks (Miller & Cafasso, 1992). Male caregivers, a reported 27–30% of all caregivers (Chang & White-Means, 1991), have been more likely than female caregivers to use instrumental problem-solving strategies as part of their successful coping efforts (Seltzer, Greenberg, & Krauss, 1995). Adult children appeared to be less adversely affected by caring for a parent than were spousal caregivers (George & Gwyther, 1986). Lawton, Kleban, Moss, Rovine, and Glicksman (1989) found that caregiving satisfaction correlated with positive affect and that burden correlated with depression for spousal caregivers, but not for adult children. Thus, within caregiving families, one's relationship to the care recipient remains an important consideration.

In addition to relationship, mastery has emerged as an important characteristic that affects the caregiving experience. Pearlin and Schooler (1978) first included this construct in their research as a means for understanding the psychological resources inherent in the personality characteristics of people that enabled them to cope with the stressful consequences of social strain. Mastery, the sense that one regards one's life chances as being under one's own control, has been found to help people cope with life strains such as caregiving (Narayan, Lewis, Tornatore, Hepburn, & Corcoran-Perry, 2001; Peters-Davis, Moss, & Pruchno, 1999). The sense of mastery is enhanced when caregivers perceive a positive aspect to their caregiving (Lawton et al., 1989; Narayan et al., 2001). The association between problem-solving strategies and positive affect has benefited caregiving husbands more than wives, who more often have used emotion-focused coping strategies that were associated with low mastery and negative affect (Kramer, 1997; Rose-Rego et al., 1998).

The care recipients' status and the caregiving context change over the course of the disease within a family and vary greatly among families as well (Gitlin, Corcoran, Winter, Boyce, & Hauck, 2001; National Institute on Aging, 2000). It is unlikely that any single approach to supporting families of persons suffering from AD would be useful to all families or even to the same family over a long period of time. Understanding the variability in caregiver outcomes and developing individualized and flexible interventions remain important research objectives.

Interventions using IVR technology have been previously designed as a means for clinicians to monitor community-dwelling persons affected with chronic diseases. Automated systems have been successfully implemented to manage hypertension

(Friedman, Stollerman, Mahoney, & Rozenblyum, 1997), weight loss (Friedman, 1998), diabetes (Piette & Mah, 1997), and mental health (Baer & Greist, 1997), and to monitor the activities of daily living for homebound elders (Mahoney, Tennstedt, Friedman, & Heeren, 1999). At the time of this proposal, only ComputerLink provided information, communication, and decision support for enrolled AD caregivers by means of an Intranet-based computer system (Brennan, Moore, & Smyth, 1991). Subsequently, Brennan and associates analyzed the effects of a similar program on caregivers of persons with AIDS and noted that AD caregivers used the system much less frequently and for shorter periods, emphasizing the need to design short, easy to use interventions for this category of caregiver (McClendon, Bass, Brennan, & McCarthy, 1998). We built upon the lessons learned from the previously cited technology research and pioneered a system that integrated voice-mail telecommunications with IVR technology.

Programmatic development of the system was theory driven. From the technology field, innovation-diffusion theory suggested that there were variations in acceptance of any new form of technology (Randles, 1983). Reported organizational and personal barriers to technology adoption have included resistance to change, fear of substituting computers for people, and technical complexity (Trice & Treacy, 1988). These insights provided the rationale for using the ubiquitous telephone as the intervention hub. The ordinary home telephone became the interface to a computer-mediated program of support for AD family caregivers.

From the caregiving literature, stress process theory guided the intervention development. Pearlin's model of AD caregiver's stress provided the conceptual framework for this study (Pearlin, Mullan, Semple, & Skaff, 1990). In this model, the relationships among caregiving factors contribute to the development of caregiver stress. Our specification of the model's domains was as follows: the background and context of stress (caregiving relationship), plus the stressor (care recipient's behaviors), as mediated by caregiver mastery, resulted in manifestations of caregiver stress (appraised bothersome nature of the care recipient's disruptive behaviors, anxiety, and depression). On the basis of Pearlin's model, we anticipated that both the participants' level of mastery and caregiving relationship would influence the response to the intervention. From this premise we tested the following hypotheses:

1. Caregivers in the intervention group will have less caregiving stress (caused by care recipient's disruptive behaviors, anxiety, and depression) than those in the control group.
2. Caregivers in the intervention group with low mastery will experience more intervention effects than those with high mastery.

3. Caregiving wives will show greater reduction in caregiving stress than caregiving husbands or children.

### *Automated Telecare Description—The REACH for TLC System*

The technology application developed for this project used a multisystem telecommunications-based approach to help caregivers manage Alzheimer's related disturbing behaviors that are commonly associated with caregiver stress, such as wandering, hitting, resistance, and outbursts. Because caregivers have diverse needs and preferences, the intervention was designed to offer multiple components with flexibility in order to effectively appeal to a variety of users. Participants chose the type of component, frequency, duration, and timing of the usage.

The technology consisted of an integrated telephone network system and an IVR computer network system. Caregivers used a confidential password to access the intervention system and to protect their anonymity. Caregivers dialed in from any standard touch-tone telephone and heard the narrator greet them by name, review the menu of four module options, and provide the service they requested. The telephone network operated the Personal Mailbox and Bulletin Board modules, similar to standard voice messaging systems. The IVR system operated the weekly caregiver conversation and the care recipient distraction call. In the IVR system, the caregiver heard a digitized human voice (we used a professional radio announcer as the narrator to ensure a pleasing voice recording) that spoke a computer-mediated script. Caregivers responded to the questions and comments they heard by pressing designated numbers on their touch-tone key pad, such as 1 for yes and 2 for no. The IVR system contained the necessary hardware to process the narrator's messages for encoding in the databases used to store and update files. The intervention was available 22 hr a day, except for 2 hr during the night for network file backup. A Technical Helpline allowed caregivers to report system problems. Detailed descriptions of the intervention architecture and system operations and the content development process have been described previously (Mahoney, 1998; Mahoney, Tarlow, & Sandaire, 1998).

The following system modules were available to participants.

*Weekly Caregiver's Conversation.*—This automated IVR conversation monitored the caregiver's stress levels and provided information on how to manage the care recipient's behavioral problems. The system narrator queried the caregiver about any disturbing behaviors exhibited by the care recipient and, if desired, provided the caregiver with information and strategies to reduce the reported

behavior(s). For example, if they agreed that “losing things” was currently a disturbing behavior, they would be offered tips on ways to specifically manage that kind of behavior in their family member. Subsequent calls assessed the responses to the problem-solving strategies and, if the behavior continued, offered additional strategies as well as a suggestion to also consider using the voice-mail system to query the expert panel or other caregivers. If caregivers reported that the problem behaviors continued and their stress levels significantly increased during a 3-week period, the computer generated an alert to our system manager. If the situation was confirmed, the manager faxed a report that graphed the increased stress by week, as well as the types and frequency of bothersome AD behaviors during this period, to the designated provider. The module also contained a monthly caregiver self-health assessment component, as well as reminders about the advice and resource features.

*Personal Mailbox.*—This allowed caregivers to anonymously send and receive confidential communications through voice mail among themselves or to communicate with a clinical nurse specialist who directly answered or triaged questions to a multidisciplinary professional panel of AD experts.

*Bulletin Board.*—This was an in-home telephone support group that provided personal and caregiver group voice mail, similar to a computer chat group. System users could anonymously post messages and receive responses back from other users.

*Activity-Respite Conversation.*—This was a care recipient distraction module designed to reduce disruptive behaviors and to provide caregivers with respite time. When initiated by the caregiver, this module offered the care recipient a personalized pleasant conversation designed to engage the listener in a safe, comforting, and nondemanding activity. The conversation lasted 18 min and would repeat once if not disconnected. Although the module offered a generic conversation, the person’s favorite hobbies, foods, holidays, friends, and songs were included as “donuts.” That is, the computer would automatically insert personally tailored data triggered by the user’s password entry.

## Methods

### *Study Design and Sample*

The Resources to Enhance Alzheimer’s Caregiver Health for Telephone-Linked Care (REACH for TLC) project was an 18-month randomized controlled study designed to test the feasibility and effect of a computer-mediated telecommunications system with a sample of AD caregivers. Caregivers were

eligible to participate if they were over the age of 21, provided 4 or more hr per day of assistance or supervision for a minimum of 6 months to a family member with AD who had at least two impairments of instrumental activities of daily living (e.g., driving, shopping, or managing money) or one activity of daily living (e.g., toileting, bathing, eating), and exhibited at least one AD-related disturbing behavior. AD was defined as having either a medical diagnosis of probable AD or of cognitive impairment with a Mini-Mental Status Exam (MMSE) score of 23 or less (Folstein, Folstein, & McHugh, 1975) collected within the past 4 months. Respondents recruited directly from the community were asked to report whether there was an established diagnosis and screened in if yes, and the MMSE collected at baseline affirmed their eligibility. Caregivers were required to have touch-tone telephone service, and a touch-tone phone was provided if needed. Persons were excluded if they had plans to institutionalize the family member within 6 months, were participating in another clinical intervention study for caregivers, were terminally ill, or refused consent. Institutional Review Board (IRB) approvals were obtained from two academic medical centers and two research institutes prior to the start of the field work, and yearly IRB reviews and approvals were maintained over the course of the study.

The participants were recruited by referrals from cooperating health and social agencies, including large urban medical centers and small clinic practices, as well as individual responses to media notices about the study (Tarlow & Mahoney, 2000). Participants were recruited from the community over a 22-month period between 1997 and 1999 and included individuals from eastern Massachusetts, southern New Hampshire, and northern Rhode Island. These efforts resulted in 143 contacts, of which 118 met the eligibility criteria and 100 participants were enrolled, for a recruitment rate of 85% (yield). Of those enrolled, 73 participants were recruited through academic medical centers, 15 were from community-based adult day care programs and AD support groups, and 12 were self-referrals from the community. The majority of persons declining participation (18) said they were too busy to participate in the project, and several reported their own physical health problems as reasons for not participating. Of the 100 enrollees, 49 were randomly assigned to the intervention group and 51 to the control group.

### *Study Protocol*

A research assistant, who was a certified REACH project interviewer, visited participants in their homes to obtain a signed informed consent and to administer the baseline interview. After the completion of the baseline data, the interviewer opened an envelope that contained the group assignment. Two separate computer-generated random assignment

lists, one for men and one for women, were generated for each recruitment site, ensuring that each intervention and control group was balanced by gender and site. Those assigned to the intervention group received instruction on use of the intervention and were given a user's manual. The research assistant demonstrated use of the system and had the participants practice until they could demonstrate correct access to the system and each of the modules. This process took, on average, 20 min. The research assistant also rated (low to high) the participants' proficiency level when they used the system, and low-proficiency users were offered additional training. Participants were encouraged to use all modules, with emphasis on the Weekly Caregiver Conversation, as this module was designed to help caregivers manage the specific disruptive behaviors they reported as being their primary source of caregiver stress. The intervention group had access to the system for a 12-month period, after which their passwords were disabled. Control group participants were given a reference booklet, containing similar content to Module 1 of the intervention, that provided strategies to manage AD-related disruptive behaviors. All participants were subsequently interviewed at time points of 6, 12, and 18 months by different telephone interviewers who were blind to the study assignments except for the user satisfaction survey at the completion of the intervention period.

## Measures

**Background Variables.**—Standard demographic measures and salient background information measures were obtained, including age, gender, and years of education for both the caregiver and care recipient. Caregivers were asked about their race or ethnicity and employment status. Caregiver relationship was self-reported by caregivers as wife, husband, or child. The care recipients' cognition was measured by Folstein's MMSE score (Folstein et al., 1975), which ranges between 0 and 30, with a cutoff point of 23 or less indicating cognitive impairment. The care recipients' functional abilities were measured by a modified Activities of Daily Living scale (Katz, Maskowitz, Jacobsen, & Jaffe, 1963) and scored between 0 and 8, with higher scores indicating greater functional impairment; and the Instrumental Activities of Daily Living scale (Lawton & Brody, 1969), with scores ranging between 0 and 6 and with higher scores indicating greater functional impairment. The results are reported in Table 1.

Mastery was assessed with the Caregiver Mastery scale (Pearlin & Schooler, 1978). This measured the extent to which the participant regarded his or her life chances as being under his or her own control in a series of seven items. Responses were indicated on a 5-point ordinal scale of 1 = strongly disagree to 5 = strongly agree, with lower scores indicating greater mastery; two items were reverse scored (Cronbach's

$\alpha = .71$ ). Scale items included the following: 1, I have little control over things that happen to me; 2, there is no way I can solve some of the problems that I have; 3, there is little I can do to change many of the important things in my life; 4, I often feel helpless in dealing with the problems of life; 5, sometimes I feel that I'm being pushed around in life; 6, what happens to me in the future mostly depends on me; and 7, I can do just about anything I really set my mind to do.

We used this measure of mastery to identify participants that were comfortable with their caregiving role, and those who were more uneasy, by classifying individuals with mastery scores 0.5 standard deviations above the mean as high, and the remainder as low-mid mastery caregivers. We used this low-mid versus high mastery variable to investigate possible interactions between baseline mastery and the effectiveness of the intervention in terms of caregiver ratings of bothersome behaviors, depressive symptoms, and anxious complaints.

**Outcome Variables.**—Three outcome variables related to caregiver stress were examined: bothersome nature of the care recipient's disruptive behaviors, anxiety, and depression. The mediating effect of caregiver mastery was also examined.

Bother was measured by the Revised Memory and Behavior Problems Checklist (RMBPC; Teri et al., 1992). This measure assessed the type and frequency of care recipient disruptive behaviors and the caregiver's appraisal of distress generated by those behaviors. Caregivers were asked whether their care recipients manifested any one of 24 problem behaviors, yes or no, during the past week. The nine-item disruptive behaviors subscale was used in this analysis because the intervention was designed to help reduce and manage care recipient disruptive behaviors. The RMBPC's Bother scale contained questions that asked how much potential disruptive behaviors might bother the caregiver. If caregivers reported the presence of a disruptive behavior, they were asked how bothered or upset they were by each behavior, using a 5-point scale ranging from 0 = not at all to 4 = extremely bothersome. Average upset scores were calculated, with an assignment of "no upset" to behaviors not manifested. Scores ranged from 0 to 36, with higher scores indicating more distress. Cronbach's alpha coefficient for the disruptive behaviors subscale of the RMBPC was .66.

Anxiety was measured by the State Anxiety Inventory (STAI; Spielberger, Gorsuch, Lushene, Vagg, & Jacobs, 1985). This 10-item measure was taken directly from Spielberger's larger State-Trait Personality Inventory. Respondents were asked how much they agreed with statements such as "I feel nervous" for the time interval of "during the past week." Response options ranged in intensity from 1 = not at all to 4 = very much. Four items were

Table 1. Caregiver and Recipient Characteristics for Intervention and Control Groups: REACH for TLC Study

Variable	TLC (Intervention)		Control Group		<i>F</i> or $\chi^2$	<i>df</i>	<i>p</i>
	<i>n</i>	%	<i>n</i>	%			
<b>Caregiver characteristics</b>							
Age in years ( <i>M</i> ± <i>SD</i> )	61.4 ± 13.6		63.7 ± 11.8		<i>F</i> = 0.8	1	.378
Sex					$\chi^2$ = 0.7	1	.390
Female	40	82	38	75			
Male	9	18	13	26			
Ethnicity					$\chi^2$ = 4.4	3	.226
White	38	78	41	80			
Black or African American	7	14	9	18			
Hispanic	2	4	0	0			
Other ethnicity groups	2	4	0	0			
Employment					$\chi^2$ = 5.0	4	.290
Full-time	8	16	9	18			
Part-time	5	10	12	24			
Homemaker	9	18	7	14			
Retired	23	47	22	43			
Unemployed	4	8	1	2			
Relationship to care recipient					$\chi^2$ = 2.4	3	.497
Spouse	27	55	27	53			
Child	17	35	21	41			
Sibling	2	4	3	6			
Other relation	3	6	0	0			
Years of education					$\chi^2$ = 0.5	2	.775
<High school	3	6	5	10			
High school diploma	15	31	16	31			
>High school	31	63	30	59			
<b>Care recipient characteristics</b>							
Age in years ( <i>M</i> ± <i>SD</i> )	75.7 ± 9.0		79.2 ± 7.6		<i>F</i> = 2.3	1	.136
Sex					$\chi^2$ = 0.0	1	.835
Female	23	47	25	49			
Male	26	53	26	51			
Years of education					$\chi^2$ = 3.5	2	.178
<High school	11	23	15	31			
High school diploma	21	45	13	27			
>High school	15	32	21	43			
Mastery score ( <i>M</i> ± <i>SD</i> )	3.6	0.8	3.4	0.9	<i>F</i> = 2.03	1	.157
MMSE score ( <i>M</i> ± <i>SD</i> )	11.6	7.6	11.2	9.0	<i>F</i> = 0.1	1	.817
ADL score ( <i>M</i> ± <i>SD</i> )	3.5	2.0	3.3	2.2	<i>F</i> = 0.1	1	.706
IADL score ( <i>M</i> ± <i>SD</i> )	7.6	1.1	7.3	1.2	<i>F</i> = 0.9	1	.342

Notes: *N* = 100. REACH = Resources to Enhance Alzheimer's Caregiver Health; TLC = telephone-linked care; MMSE = Mini-Mental Status Exam; ADL = activities of daily living; IADL = instrumental activities of daily living.

scaled negatively; a "very much" response would indicate a low level of anxiety, such as "I am relaxed." Cronbach's alpha coefficient for the anxiety measure was .89.

Depression was assessed with the Center for Epidemiological Studies Depression scale (CES-D; Radloff, 1977). This 20-item measure asked about the frequency with which respondents experienced depressive symptoms within the past week. Response options ranged from 0 to 3, as follows: 0 = rarely or none of the time (less than 1 day), 1 = some or a little of the time (1–2 days), 2 = occasionally or a moderate amount of time (3–4 days), and 3 = most or all of the

time (5–7 days). Cronbach's alpha coefficient for the CES-D was .89.

### Analysis

Bivariate analyses were used to provide descriptive data and to evaluate the adequacy of randomization. Tests of intervention effectiveness were addressed with a repeated measures approach to longitudinal data. The aim was to evaluate the extent that the intervention modified the trajectory of caregiver-reported behavioral problems (RMBPC disruptive behavior subscale), depressive symptoms

(CES-D), and anxiety (STAI), and whether this varied by level of mastery at baseline. We originally chose to cut mastery at half a standard deviation above and below the mean to form three groups of low, mid, and high mastery of roughly equal size. After initial analyses revealed little difference between the low and mid groups, these groups were combined for the sake of presenting results that followed the principle of parsimony. We used a generalized estimating equations approach with the four assessments (baseline, 6-month interim, 12-month intervention endpoint, and 18-month carry-over effect) for each of the three outcomes. An exchangeable correlation structure was used to model the nonindependence of repeated observations within subjects and include all assessed participants under the assumption that the mechanism of missingness is completely random (Little & Rubin, 1987). We explored other autocorrelation structures (e.g., autoregressive ones), which returned qualitatively identical results. We explored linear, quadratic, and piecewise normative trajectories for the three outcomes, and we found that a linear function provided the best fit to the observed data (based on  $-2 \times \log$  likelihood). Therefore, all results presented describe a linear effect of time. Main effect models were generated by regressing the repeated observation of RMBPC, CES-D, or STAI on three independent variables: intervention status, time, and the interaction of time and intervention status. The significance of the intervention effect is captured with the regression parameter associated with the interaction of time and intervention status, and this is summarized in Figures 1 and 2. Analyses were conducted with the STATA statistical software package (Stata Corp., 1999). Results of these models are summarized with figures displaying the model-implied trajectory for the outcome variables.

## Results

We enrolled and randomized 100 caregiving dyads (49 in the TLC group and 51 in the control group), all of whom had a care recipient with a medical diagnosis of probable AD or a MMSE score of 23 or less. There were no significant differences in characteristics between the control and intervention groups for either the caregivers or the care recipients enrolled in the study (Table 1). Just 80% of the caregivers in both the intervention and control groups were women, with a mean age of approximately 62 years. The majority of caregivers were White, and the largest percent were retired. Most caregivers were the spouses of the care recipients.

The care recipients in the intervention and control groups included nearly equal numbers of women, and they were similar in age. The care recipients were very similar in mastery scores, MMSE scores, activities of daily living scores, and instrumental

activities of daily living scores. Differences were noted in educational background, although none were significant. More of the control group participants had either less than or more than a high school education.

We had high participant retention in both groups over time. Caregivers that discontinued the study, or for whom the care recipient died or was institutionalized over the course of the study, did not differ significantly in terms of baseline ratings of bothersome behavior, burden of depressive symptoms, or presence of anxious symptoms.

Table 2 summarizes the means, standard deviations, and numbers of care recipients providing main outcome data at baseline and three follow-up visits. Missing data was more pronounced for the RMBPC, because this scale was not asked of caregivers for whom the recipient had died or was institutionalized during the interwave period. There was no significant difference in the frequency of missing data between intervention and control groups for the outcome measures presented in Table 2 ( $p > .05$ ). The intervention and control groups did not differ significantly for any of the outcome dimensions at baseline ( $p > .05$ ).

### Intervention Effect

Hypothesis 1 postulated that the intervention group would experience reduced caregiver stress, and this was not supported. Overall, there was no significant main effect of the intervention in reducing bother scores (RMBPC), depression (CES-D) scores, or state anxiety (STAI; Figure 1). Trajectories did not differ overall for control group and intervention group participants, as displayed in Figure 1.

Hypothesis 2 tested whether treatment effects would vary among participants with low to mid mastery versus those with high levels of mastery. Subgroups based on Pearlin's mastery measure included those with low to mid levels of mastery (up to 0.5 *SD* above the overall sample mean) and those with high level of mastery (a mastery level more than 0.5 *SD* above the mean) at baseline. There was a significant intervention effect for all three outcomes for participants with low-mid mastery at baseline. These effects are summarized in Figure 2. Participants with low-mid mastery at baseline experienced a greater decline in RMBPC bother scores, CES-D depressive symptoms, and STAI anxious complaints over the 18-month study period relative to controls. There was no significant difference ( $p > .05$ ) between rates of change in the study outcomes for participants with high mastery at baseline (results not shown).

Hypothesis 3 suggested that wives would differ in response from other caregivers, and this was partially supported. There was a significant intervention effect for caregivers who were wives, for RMBPC scores ( $p = .023$ ; results not shown). There

Table 2. Main Outcomes by Wave and Intervention Group Status: REACH for TLC Study

Variable (measure)	TLC (Intervention)			Control Group		
	<i>n</i>	<i>M</i>	<i>SD</i>	<i>n</i>	<i>M</i>	<i>SD</i>
Bothersome behaviors (RMBPC)						
Baseline	49	14.9	14.4	51	11.1	10.3
6-month follow-up	36	11.5	9.4	42	12.8	11.2
12-month follow-up	28	14.1	11.9	32	10.3	11.1
18-month follow-up	22	12.2	11.0	23	12.3	13.1
Depressive symptoms (CES-D)						
Baseline	49	13.7	11.1	51	13.5	11.0
6-month follow-up	45	12.3	9.1	48	14.9	11.7
12-month follow-up	40	12.4	11.5	46	13.6	12.0
18-month follow-up	39	12.0	10.3	43	14.5	11.7
Anxious symptoms (STAI)						
Baseline	49	20.9	6.8	51	20.9	6.6
6-month follow-up	45	19.8	5.7	48	20.6	7.7
12-month follow-up	40	20.2	6.8	46	20.7	7.5
18-month follow-up	39	19.0	6.5	43	20.7	7.6

Notes: *N* = 100. REACH = Resources to Enhance Alzheimer’s Caregiver Health; TLC = telephone-linked care; RMBPC = Revised Memory and Behavior Problems Checklist; CES-D = Center for Epidemiological Studies Depression scale; STAI = State Anxiety Inventory.

was no significant difference in treatment effectiveness for any of the other outcomes within any of the other relationship groups.

## Discussion

The present study examined whether an automated telecommunications system designed for AD caregivers exerted positive effects on caregiver outcomes. The system aimed to reduce caregivers’ stress related to managing their care recipients’ bothersome behaviors associated with AD. We did find significant intervention effects for caregivers with lower mastery at baseline and for those who were wives. As previously cited research indicated, wives provide the majority of family caregiving, and interventions that support their role and reduce negative caregiver outcomes are important. The IVR intervention did have the effect of reducing the bothersome nature of dementia-related behavioral disturbances for wives of surviving care recipients that maintained residence in the community. Findings from this research lend support to further considerations of using the telephone as a means to reduce this particular form of caregiver stress. Moreover, another important category of participants, those with low caregiving mastery, demonstrated the most reduction in caregiver stress-related outcomes of bothersome behaviors, depression, and anxiety. Prior IVR technology research has found beneficial results for people who are uncomfortable with in-person face-to-face counseling situations (Baer & Greist, 1997). Findings from this study contribute insights into the characteristics of the subgroups of caregiving users who most benefit from IVR interventions. Previous research has suggested the need for technology

developers to study and share such characteristics to help advance the technology field (McClendon et al., 1998).

There are several possible explanations for the lack of an overall main effect from the intervention. One of our study eligibility criteria required that the caregivers report at least one bothersome behavior at minimum, and we expected many more. Participants, however, not only reported, on average, low baseline total bother scores, but also low depression scores (See Table 2.). With such low values, we experienced floor effects, wherein there was little room to further lower these values in a meaningful way. Whitlatch, Zarit, and von Eye (1991) specifically noted that someone with an initially low score of depression can only worsen and suggested that a regression to the mean results in an underestimate of the impact of the intervention. Furthermore, the intervention was designed to follow a consumer choice approach that offered users a selection of four modules to choose from, and we expected differential usage based on the users’ preferences. Consequently, the intensity of the intervention delivery varied even among users. Biegel, Sales, and Schulz (1991) suggested a greater likelihood of effectiveness from interventions that offer both high intensity and long duration. Our caregivers chose the opposite pattern, one of low intensity and short duration. On average, usage was concentrated to the first 4 months and amounted to 55 min/user (*SD* = 78 min) over the 1-year period (range 1–318 min), with calls numbering between 1 and 45 (11 on average) and lasting per call for 3 min and 40 seconds (Mahoney, Tarlow, Jones, Tennstedt, & Kasten, 2001).

Another factor was that the majority of participants enrolled through referrals from academic



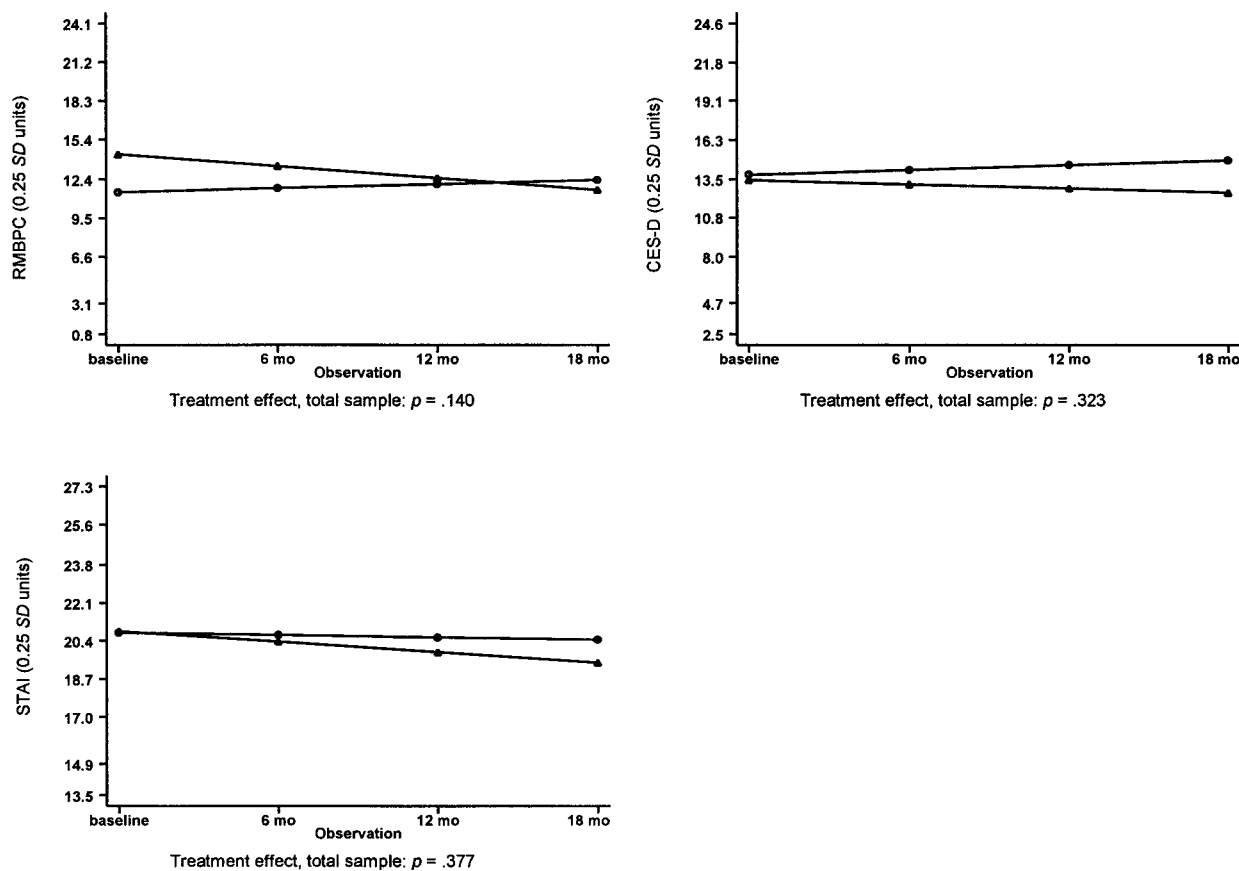


Figure 1. Main intervention effect for ratings of bothersome behavior (Revised Memory and Behavior Problems Checklist, or RMBPC bother), depressive symptoms (Center for Epidemiological Studies Depression scale, or CES-D), and anxiety symptoms (State Anxiety Inventory, or STAI). The range of the y axis includes the mean  $\pm 1$  SD, marked in 0.25-SD units based on the distribution of the total sample at baseline. Lines plotted are model-implied trajectories for the outcomes for treatment and control groups derived from a generalized estimating equations model with an exchangeable correlation structure;  $p$  values refer to the significance of the interaction between the intervention group and time. Significant values ( $p < .05$ ) imply that the rate of change is different in the control and intervention groups. ● Control group,  $n = 51$ ; ▲ Intervention group,  $n = 49$ .

medical centers where they had access to Alzheimer's specialty teams for information and assistance. It is plausible that a sample without similar easy access to Alzheimer's experts would have used the system more and in a different manner. This has some modest support on the basis of our observations that greater usage occurred among a small subset of users from rural New Hampshire and that many caregivers from academic medical centers reported no difficulty in obtaining information and advice from their AD specialists, physicians, and nurses.

The final factor related to sample underenrollment and inadequate power for the outcome analysis. We were constrained by participating in a multisite study of various caregiver interventions that required us to adhere to a short recruitment schedule and a longitudinal design that became uniquely problematic in our region. We previously conducted a substudy of REACH-eligible refusers and found that many caregivers would not commit to the 12-month caregiver intervention program and postintervention follow-up at 18 months because this study excluded them from the Alzheimer's clinical

drug treatment trials underway in our locale (Tarlow & Mahoney, 2000). These caregivers strongly preferred participating in the clinical drug trials. Consequently, we needed a longer recruitment period, but this was not in keeping with the multisite recruitment schedule and we were stopped from extending our recruitment. In addition, as a result of technical difficulties, the TLC system failed to record data on some of the subjects, further reducing the analytic sample (Mahoney, 2000). Thus, although our sample size was adequate for the technical feasibility analysis, it was less than desired for the caregiver outcome analyses, and this strongly contributes to the possibility of a Type II error, or an underestimation of an effect.

Although not directly tied to the intervention, the fact that there was very little change in reports of bothersomeness of behaviors or depressive and anxious symptoms over the 18-month period in AD caregiver's careers was a notable finding. This observation speaks to the need to more fully understand the developmental trajectory of ratings of bothersome behaviors and destabilization of

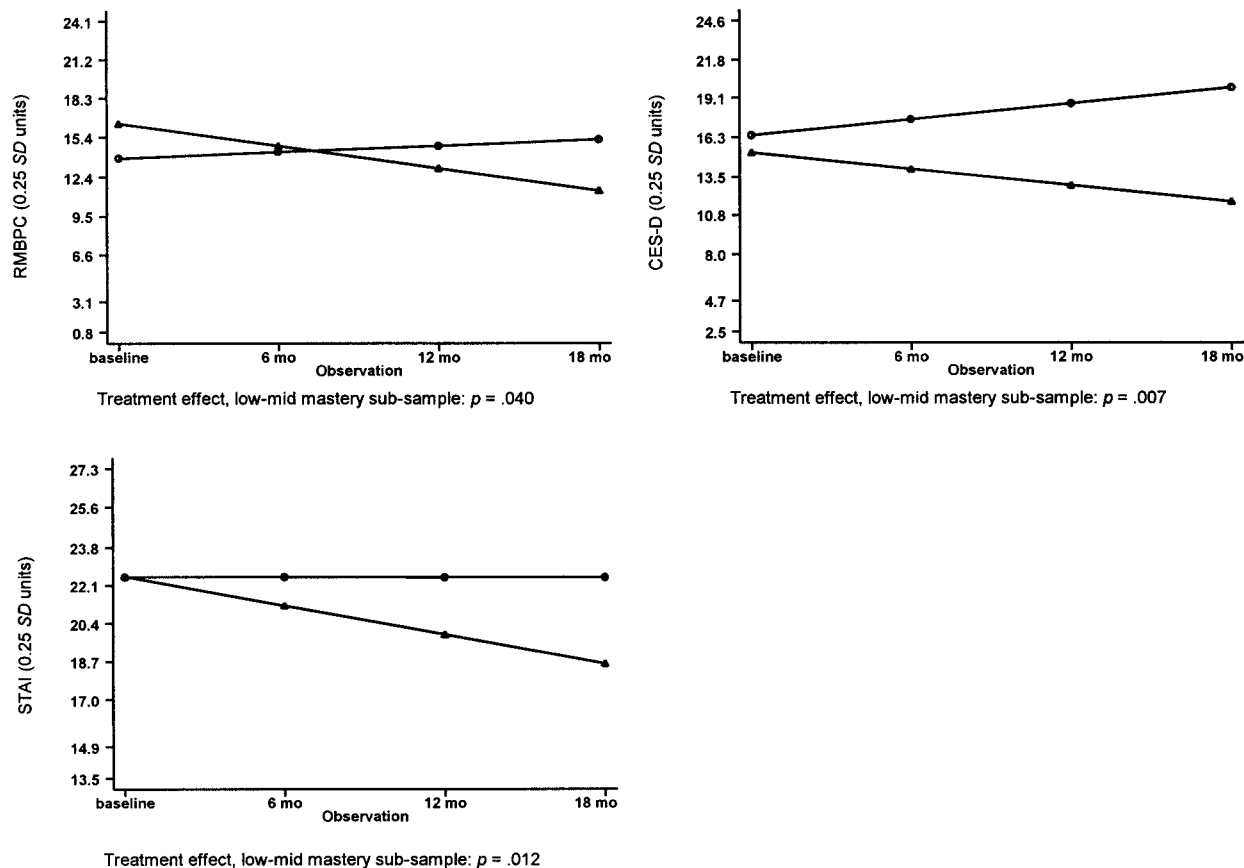


Figure 2. Intervention effects, limited to participants with low-mid mastery (Pearlin, 0.5 SD above the total sample mean or less) at baseline for bothersome behavior (Revised Memory and Behavior Problems checklist, or RMBPC bother), depressive symptoms (Center for Epidemiological Studies Depression scale, or CES-D), and anxious symptoms (State Anxiety Inventory, or STAI),  $n = 32$  all three groups. The range of the y axis includes the mean  $\pm 1$  SD, marked in 0.25-SD units based on the distribution of the total sample at baseline. Lines plotted are model-implied trajectories for the outcomes for treatment and control groups derived from a generalized estimating equations model with an exchangeable correlation structure;  $p$  values refer to the significance of the interaction between the intervention group and time. Significant values ( $p < .05$ ) imply that the rate of change is different in the control and intervention groups. ● Control group, ▲ intervention group in all three.

mood among AD caregivers. Although it is widely reported in the literature that AD caregivers suffer greater depression than age-matched controls (National Alliance for Caregiving and American Association of Retired Persons, 1997; Schulz & Beach, 1999), the findings reported here suggest that bother and mood destabilization do not occur rapidly or continuously over the course of AD caregiving careers. Appropriate targeting of interventions requires identifying a suitable population and may include important dimensions such as nature of relationship, length of caregiving, and sense of mastery over the caregiving situation. Future research is needed that explores the natural course of important dimensions of caregivers' biopsychosocial responses over the duration of caregiving careers, results of which are critical for timing and maximizing intervention benefits.

Moreover, findings from our prior analysis of TLC features and usage complement the present outcome analyses, and together these studies provide important insights to the further understanding of

the strengths and limitations of this technology-based intervention (Mahoney et al., 2001). For example, we did not previously find the integrated voice-mail bulletin board, personal mail box, and professional triage features to be necessary components, and we believe streamlining them in future applications would decrease the system's development cost, complexity, and likelihood of technical problems (Mahoney, 2000; Mahoney et al., 2001). The respite call, however, was a feature highly valued by those who perceived the need for and allowed the care recipient to use it. We did find that users needed to perceive a personal reason or clear purpose to motivate them to adopt using the system. Training until proficiency was demonstrated became a critical component of this adoption and is strongly recommended. Users preferred short conversation-style interactions with advice and counseling on demand for up to a 4-month time period, after which there was negligible usage (Mahoney et al., 2001). Another positive but unexpected finding occurred among a subset of nonusers who reported that they

were satisfied with the automated system. A content analysis of their comments had revealed that these participants perceived no immediate need for the system, but they valued knowing they could have accessed it if the need arose. The theme that emerged was a sense of security and comfort from knowing that a source of information and respite was available at any time, irrespective of usage. This finding suggests that availability can exert a positive influence on caregiver satisfaction and highlights the necessity to both assess and differentiate intervention availability from actual usage. By contrast, unsatisfied nonusers unequivocally expressed their strong preference for personal interactions with humans. Moreover, they had expressed this reluctance to use IVR technology at the baseline interview and this was highly predictive (Mahoney et al., 2001).

In summary, this study uniquely contributes to both the fields of Alzheimer's caregiver and telecare intervention research. The intervention was innovative in several aspects; it was completely automated, operated with immediate availability 7 days a week, and was not limited by traditional daytime working hours or the 40-hr a week work schedule. REACH for TLC offered consistent high-quality information without the variability associated with different interventionists and human factors such as fatigue or forgetfulness. The technology permitted the delivery of the content through a consumer choice approach without the need for or control by professionals. The system was not limited by staff availability or turnover. Contrary to prevailing beliefs, a low-intensity intervention did exert an effect. This is an important finding that suggests that high intensity, professionally mediated interventions can be modified to address the reimbursement and other practical barriers that deter adoption of new programs in real-world situations. From the technology side, the REACH for TLC system was the first application that demonstrated the feasibility of merging voice-mail subsystems with IVR technology, and, beyond that, went on to determine the components that were most useful. To our knowledge, it was the first IVR application to study Alzheimer's caregiver outcomes and to identify both the characteristics of the users and their patterns of usage over a 12-month period.

Future caregiver telecommunications research should seek to find the optimal mix of technology, content information, and human interface. Would an IVR system with more intensity by means of scheduled sessions or special sessions mediated by a human interventionist exert stronger outcome effects and appeal to more of the nonusers? For a clinical application, we suggest integrating the system into a network of clinical providers, linking to staff members for advice instead of an unfamiliar external expert panel. This would diminish the providers' resistance to technology, caused by fears

of computer substitution for their caregiver services and loss of clients, that we and others have encountered (Mahoney et al., 2001; Slack, 1997). For maximal effectiveness, we suggest that clinicians should target caregivers who foresee a need for the technology (either presently or in the near future), are interested in becoming proficient users, and portray the personal characteristics associated with positive outcomes.

In conclusion, the outcome analyses revealed that those most likely to benefit from the REACH for TLC system were wives who exhibited low mastery and high anxiety. The system was able to decrease the bothersome nature of the care recipients' AD-related disturbing behaviors in this subset of critically important caregivers, and they appear particularly suited to this telecare application.

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Received May 9, 2002

Accepted September 17, 2002

Decision Editor: Laurence G. Branch, PhD