

COACH MANUAL
The Dementia Caregiving Skills Program:
*Reducing Stress and Enjoying Time
With Your Family Member*

Authored by:

Judith R. Gant, Ph.D.
Ann M. Steffen, Ph.D.
Amy K. Silberbogen, M.A.
Dolores Gallagher-Thompson, Ph.D.

A program developed at The University of Missouri-St. Louis
and sponsored by the National Institute of Mental Health

©2001

PART 1: INTRODUCTION

Theoretical Framework of the Dementia Caregiving Skills Program

Increasing Pleasant Events

The intervention first focuses on increasing pleasant events, based on Peter Lewinsohn's Social Learning Theory of Depression (Lewinsohn et al., 1978). This section of the project relies on two tenets of Lewinsohn's theory that have consistently been supported by empirical studies:

1. A scarcity of positively reinforcing daily events (i.e. pleasant events) eventually results in a decline in overall level of daily mood.
2. As mood declines, there is an increasing tendency to avoid potentially pleasant daily events which, in turn, further lowers daily mood. The avoidance of potentially pleasant daily events seems to occur because such events and activities are not perceived to be as positive as they once were. This avoidance of pleasant events and resultant decline in mood has been called the "vicious circle effect."

The application of these two mechanisms to caregiver stress is straightforward. The daily tasks performed by individuals caring for a frail elder are often unpleasant and time consuming. There is little opportunity to engage in pleasant activities, and this eventually results in lowered mood (i.e., feelings of stress, burden, depression, frustration, etc.). The vicious circle effect is initiated and can eventually lead to chronically low levels of mood and an inability to continue as a caregiver.

Lewinsohn recommends that individuals who are experiencing chronically low levels of mood break out of the vicious circle effect by reinstating some pleasant events in their lives. To do this, the individuals need to learn that daily events do affect their mood and that they have at least some degree of control over the events they experience each day.

The effectiveness of increasing pleasant and meaningful activities, sometimes referred to as behavioral activation, was demonstrated in research by Jacobson et al. (1996). This study focused upon the effectiveness of components of cognitive behavioral treatment for depression. The researchers found that the component dealing primarily with increasing pleasant events was as effective as the full cognitive/behavioral treatment (increasing pleasant events, modification of automatic thoughts, and changing core unhelpful assumptions). To accomplish these learning tasks, Lewinsohn has proposed (and tested) a treatment protocol that includes self-monitoring of mood and pleasant events, and the application of problem-solving principles for overcoming obstacles to increasing pleasant daily events. Thompson, Gallagher, and Lovett (1992) have adapted this protocol for work specifically with caregivers in their *Increasing Life Satisfaction* manuals and classes. In addition, Gallagher-Thompson et al.'s (1992a, 1992b) *Controlling Your Frustration* manuals and classes encourage focusing on pleasant events as a means to decrease the frustration and stress inherent in caregiving. The behavioral activation component in the current project is based on the concepts presented in these manuals.

Behavioral Management

The second main component of the present intervention focuses on the caregiver's management of

her ill family member's difficult behaviors and is based upon a "behavioral paradigm" (Pinkston & Linsk, 1984; Teri, 1998). This paradigm has its foundations in operant and social learning theories of behavior change, whereby behavior is thought to be controlled by both a stimulus occurring before the behavior (antecedent) and a reinforcer (consequence) that follows the behavior (see Schwartz & Reisberg, 1991). This behavioral paradigm holds that once a difficult behavior is identified clearly, further analysis can determine the usual antecedent and consequence of that behavior. In the current intervention, particular emphasis is placed on antecedents rather than consequences.

For example, a caregiver may experience being yelled at by a demented family member. The antecedents to this problem behavior may include an inadequately lit room and hallway; poor lighting increases the patient's confusion and insecurity, which are expressed in anger. The behavioral paradigm suggests that behavioral change will occur when the antecedent is changed. In this example, changing the antecedent by modifying the environment (e.g., lighting the room and hall to decrease confusion) may *prevent* the problem. A change in consequence (e.g., redirecting the patient to doing a preferred activity) may also be helpful. As simple as this process may sound, it often requires multiple attempts to determine the effective strategy for behavioral change.

Although this behavioral paradigm stresses the influences of antecedents and consequences upon behavior, other factors such as health may also affect the dementia patients' actions. The cognitive impairment that is the hallmark of dementia can be, in itself, a predisposing antecedent that is exacerbated by a particular situation. For example, impaired processing of sensory information is always a problem for individuals with dementia, but this difficulty may be worsened by certain environmental conditions. Many individuals with dementia have insufficient cognitive resources to *learn* from a changed consequence, although some strategies (e.g., redirection or distraction) may be helpful. Therefore, *preventing* the problem by changing the antecedent is often preferable to changing the consequence. The promise of this behavioral paradigm for individuals with dementia has been demonstrated by research projects in which caregivers of patients with brain disorders were taught to modify their family members' problem behaviors (Pinkston & colleagues, 1988; Pinkston & Linsk, 1984; Teri & Logsdon, 2000); in both of the Pinkston and Linsk studies over 70 percent of problem behaviors improved.

The importance of reducing both patient problem behaviors and resulting caregiver stress has been demonstrated in the caregiver literature. A study of dementia patient caregivers found that troublesome patient behaviors and caregiver reactions to those behaviors were predictive of actual institutionalization (Cohen et al., 1993). A review of the caregiver literature by Schultz et al., (1995) reports, "The one patient characteristic that overwhelmingly predicted caregiver depression was the degree to which the care recipient evidenced behavioral problems, such as wandering, screaming, or destroying property," (p. 784). These studies make a strong case for interventions that assist caregivers to change problem behaviors.

Relaxation Training: Cued Controlled Breathing

The third primary component of this program teaches the caregiver stress reduction techniques. In particular, caregivers are taught cued controlled breathing. The rationale for this stress reduction strategy was developed by Herbert Benson, M.D. in his research and clinical work at the Harvard Medical School and Boston's Beth Israel Hospital (1975, 1984). His studies provided robust demonstration of cued relaxation's efficacy for counteracting stress and its detrimental health effects (e.g., headaches, hypertension, and inhibition of the immune system). Caregivers' decreased immune response compared to well-matched noncaregivers has been documented by researchers

(Kiecolt-Glaser & Glaser, 2001). The detrimental effects of stress therefore make cued relaxation important for the enhancement of caregivers' health, their stress management skills, and their effective use of this program. In a pilot study in which cued controlled breathing was taught, caregivers uniformly identified the relaxation training as most helpful in their follow-up session (Steffen, 2000). Throughout the intervention, additional stress reduction techniques are also presented (i.e., positive self talk and coping cards).

Basic Education and Video Series/Workbook/Telephone Interventions

Basic Education Condition: Control Condition

Caregivers in the Basic Education (comparison) condition receive the *Basic Care Guide: A Resource for Caregivers* developed by the Alzheimer's Association of St. Louis (1999). The Basic Education condition is meant to emphasize the use of written information with minimal staff contact.

Caregivers in this condition are instructed to read the educational care guide over a 14-week period. A staff member contacts caregivers in the control group every two weeks for a brief five to ten minute phone call. During this phone call, the staff member checks in with the caregiver to determine if they have read a section of the care guide over the past two weeks. In addition, the staff member asks the caregiver if she has tried any suggestions or found the care guide to be helpful. Finally, the staff member answers any questions that the caregiver has about the basic care guide, referring the caregiver back to the care guide whenever possible. The staff member also refrains from engaging in problem-solving or offering advice/suggestions. If the caregiver expresses frustration with the care guide or the program, staff members are encouraged to acknowledge their frustration and reemphasize the importance of their involvement in the program.

Video Series/Manual/Telephone Coach Contact: Treatment Condition

Caregivers in the video series condition receive the 10-session video series and a manual developed specifically for this program (Steffen, Gant, Coon, Gallagher-Thompson, Thompson, Burgio, & Stevens, 2001a & 2001b) and weekly telephone calls from a trained coach. These three components of the treatment condition are described below in detail.

Each session of the video series includes use of a primary presenter (the Principal Investigator), guest presenters for specific components, and role-plays demonstrating specific behavioral activation, behavioral management, and stress management skills. All the examples are caregiver specific. In many of the weekly sessions, caregivers are instructed to pause the video, turn to a specific page in their workbooks, and complete a worksheet or answer a question.

The accompanying workbook provides reading material and exercise worksheets. For each session, several pages of related didactic reading materials are provided. This text was written specifically for the workbook and was designed for easy understanding (e.g., 6th grade reading level and frequent use of subheadings and summaries). The workbook also includes completed examples of worksheets that correspond to the specific self-monitoring and skill-practice exercises discussed in the video (e.g., tracking number of pleasant events per day or identifying antecedents of problem behaviors). Also included in the workbook are blank pages where participants can take notes as they watch the video.

Together, the video series and accompanying workbook were developed with older adults in mind

and use several modifications of treatment strategies to accommodate differences between younger and older adults. These modifications include a slower pacing of material, repetition, and multi-modal presentation of material (Zeiss and Steffen, 1996).

A weekly telephone call is made by a trained coach who assists the caregiver with each session's skill development. In each telephone session, the coach and caregiver will review progress on the exercises from the previous week and problem-solve any difficulties related to (a) finding uninterrupted time to watch the video and do the reading; (b) understanding the concepts and suggestions provided in the week's video; and (c) practicing the behavioral skills demonstrated in the video series. Phone sessions will average approximately 30 to 50 minutes depending on the content of the week's work and the relative strengths of the caregiver. In addition to the ten weekly phone calls that correspond to the video presentations and manual materials, the coaches will provide two additional problem-solving telephone sessions. These two sessions will occur two weeks and four weeks after the video series is completed. An overview of the telephone sessions are provided on page 15 of this introductory section and a detailed script is provided in Part 2 of this manual.

Caregivers will be encouraged to call between scheduled weekly sessions if problems with the project material arise. Telephone sessions will be audiotaped for adherence/competency monitoring. Confidentiality will be maintained by limiting use of tapes for the sole purposes of training and monitoring of adherence/competency; audiotaped sessions will be kept in a secure location.

When appropriate, the coach will provide caregivers with additional materials by mail. These materials may include, for example, revisions of assignments (e.g., plans for changing problem behaviors) or hand-outs summarizing ways to solve problems developed during a telephone call.

In general, the preferred schedule for these intervention components is video-viewing by the caregiver on Day 1 of the week, "To Do" assignment completion on Days 2 through 6, and the telephone session on Day 5, 6, or 7. Coaches and caregivers will decide upon a weekly schedule so that (a) the caregiver will become accustomed to the same times each week for working on the study and (b) the coach may schedule multiple caregivers at regular times. For situations in which the caregiver upsets the schedule by watching a video at a later date, the benefits of adherence to the schedule will be balanced against the importance of the caregiver having time between the video and telephone session to work on the assignments.

Treatment Condition

Materials

Each telephone coach will need a copy of this Coach's Manual, which includes this introduction, telephone session scripts, and the appendix (Gant, Steffen, Silberbogen, & Gallagher-Thompson, 2001), the Participant Binder (comprised of Parts 2 and 3 of this Coach's Manual), the caregiver's Participant Folder which includes all caregiver-specific screening and assessment material, a copy of the video series, and apparatus for audiotaping telephone sessions.

General Guidelines for Telephone Coaching Sessions

The following guidelines apply to all telephone sessions in the treatment condition.

1. It is important for coaches to emphasize skill-building as the major goal of the program and the telephone sessions. The caregiver may feel that the telephone session is a natural place for her to

vent her caregiving experiences, emotions, and uncertainties. In the case of non-crisis caregiver or non-caregiver issues, the coaches' appropriate role is to make a referral. Beyond an initial expression of empathy for caregivers' situations, telephone coaches should usually guide caregivers to their local chapter of the Alzheimer's Association or Area Agency on Aging.

In addition, some caregivers may have a tendency to focus on particular complaints rather than session material. This behavior may make it difficult for coaches to stay on track. Coaches must resist the pressure to turn the session into supportive psychotherapy. The following techniques have proven useful in maintaining the skill-building emphasis during telephone sessions. In addition, it will be important to discuss this tendency in weekly staff treatment meetings.

A. Actively tie issues or problems mentioned by caregivers back to the goals of the program. For example, a complaint about an ungrateful family member might be redefined by the following statement, "That is a perfect example of how few naturally-occurring pleasant events caregivers usually experience and why we are working hard on ways to increase them." Closely examine problems or complaints brought up by caregivers. Many apparently unrelated issues may actually be very relevant to program content and be handled within the session.

B. If a caregiver consistently tends to pull the session off topic and the Caregiver Distress Troubleshooting techniques do not bring this tendency into tolerable limits, warmly mention this observation and ask the caregiver if she can help you understand why this is happening. It may be that the participant needs a different form of service (e.g., support group, individual therapy), and a referral can be made. Otherwise, explain the difficulties faced by the coach in covering all the material in the available time and ask for her help in keeping the sessions on task.

2. The development of an emotional connection between the telephone coach and the caregiver is important for maintaining the caregiver's motivation to participate actively in the program. Components of rapport-building include questioning, reflecting, being empathic, and normalizing. The following are examples of these components used in a situation of a spousal caregiver notified by a hospital that her mother has had a stroke.

A. Get more information to demonstrate that the caregiver is being taken seriously. (Example: "What kind of symptoms was she showing that led them to diagnose a stroke?")

B. Reflect back to the caregiver her concern. (Example: "So, this was a terrible shock. And, in the midst of everything else that you needed to be doing, your mom was in the emergency room, and you needed to be with her.")

C. Empathize with the caregiver's feelings. (Example: "You were really worried about her and feeling anxious about getting your husband's bathing finished. It sounds like you were feeling all alone with all these worries.")

D. Normalize the caregiver's feelings about the situation. (Example: "Boy, I think anyone would have felt the strain of meeting the really pressing needs of both your mom and your husband...not to mention the need to make arrangements for care of your husband so you could be with your mother in the hospital.")

To further increase caregiver motivation, coaches should reinforce caregivers when they have completed assignments and/or put significant effort towards completing assignments. Coaches should make positive comments about caregivers' assignment completion and provide encouragement on difficult tasks. Additionally, coaches should always emphasize how helpful the completion of an assignment is for coping with stressful caregiving situations (i.e., rationale for doing assignments).

3. The caregiver may not always watch the video or complete the reading as previously scheduled. In the case that the caregiver did not watch the video, it will be necessary to reschedule the telephone session. However, if the caregiver does not do the reading or exercises, the coach can continue the telephone session and follow the session guidelines, which provide for reviewing the content with the caregiver and completing the exercises together.

4. There may be occasions when a coach is pulled away from session material by a caregiver crisis (serious safety problem such as suicidal ideation). In cases of safety crises, coaches may refer to the appropriate Troubleshooting worksheets (e.g. Suicidal Ideation worksheet) and/or guide caregivers to emergency numbers for situations that are not within the scope of the protocol. Coaches should use an Off-Protocol Contact Sheet to record the basics of the crisis; the Off-Protocol Contact Sheets are to be used for any patient contact that does not involve normal study procedures.

5. Coaches will be expected to have a basic understanding of symptoms of delirium, stroke, Alzheimer's disease, and any other specific type of dementia encountered in working with a particular caregiver.

6. Coaches should be prepared for caregivers to suddenly feel overwhelmed or too busy, and subsequently, want to discontinue their involvement in the program. It is possible that they may be doing quite well in the sessions, and then suddenly want to drop out, saying, "This is too much. I need to stop." Caregivers often lead chaotic lifestyles, and while continuing to follow the protocol, coaches also need to be flexible and accommodate these times. When a caregiver states that she wants to drop, the coach should never just say, "OK." There are several intermediate steps that should be proposed and strongly encouraged. First, encourage the caregiver to take a week off (not to watch videos or do workbook), but to still schedule a phone call for the following week to check in on how things are going. Second, seek supervision from the Project Coordinator and the Principal Investigator. We have had caregivers who needed to take a break for up to two months before continuing, and we have been able to accommodate this. We can be creative in helping a caregiver complete the video series.

7. As the coaches go through the telephone coaching sessions for the video condition, keep in mind that they are not going to go through all parts of the intervention with equally detailed attention. Over time, the coach will get a sense of each caregiver's relative strengths and weaknesses, and can make decisions on where to spend the most time and energy during a phone call. The coaching sessions can get too long and become a burden to caregivers if they are routinely lasting more than 45-50 minutes. This increases the risk of them dropping out, so coaches need to monitor the length of their sessions. In general, the program is laid out so that Session 1 introduces the program, Sessions 2-4 are focused on increasing pleasant events for both the caregiver and the patient, Sessions 5-7 are focused on behavioral management, and Sessions 8-9 are focused on relaxation. Session 10 is mostly a review and future planning session. So, the coach should be more detailed in her review of the assigned exercises that are the primary focus of that part of the intervention.

8. As coaches review the reading assignments with caregivers, it may be the case that particular parts do not apply to the caregiver's situation or specific problem behavior. If this occurs, coaches should acknowledge this to the caregiver, but also reaffirm the importance of reviewing this material, so that if that particular situation develops in the future, the caregiver is more prepared. For example, a coach could say the following, "Some of these examples may not apply to the problem behavior we are working on right now. However, I think it is important to review them because they help you to better understand the six basic steps to solving a problem behavior."

9. Coaches will be expected to be familiar with the Troubleshooting worksheets before any caregiver contact to help prepare them for any crisis situations. (These sheets provide example scripts for what coaches might say.)

10. In terms of behavior management, telephone coaches should assist the caregivers to identify and describe the behavior problems exhibited by their family members in such a way that they can be monitored and changed. In general, coaches can work with the caregivers to ensure that their descriptions of the problem behaviors do not make any assumptions about the motivation or the reasons for the behavior (i.e., leave out phrases like, "she doesn't want to," or "she gets scared"). It is also helpful to avoid broad labels that do not indicate the specific behaviors involved (i.e., avoid words like "uncooperative," "manipulative," etc.). Instead, the descriptions should be directly observable (i.e., "She hit me when I asked her to hold on to the doll.") Coaches can ask questions like, "If I was a fly on the wall, or a hidden camera in the room, what would I see and hear?" The following are some examples:

"He doesn't cooperate when I'm trying to dress him." becomes

"When I am helping him change his clothes, he pushes me away and says things like, 'leave me alone'."

"She never wants to do anything." becomes

"When I ask her if she wants to go out with me for a walk or some other activity, she closes her eyes and says, 'I'm too tired'."

11. Coaches should expect to encounter some doubts over the ideas being presented. Every person is a psychologist to the extent that she has developed her own ideas about why people feel and behave the way they do. Caregivers' personal theories do not always coincide with the social learning model of mood presented in the program. It is only reasonable that they will argue for their point of view. There is a primary objective to keep in mind when trying to deal with a caregiver's difficulties with an idea. This objective is to have the caregiver maintain an open-minded attitude about the new ideas until the new strategies have had a chance to demonstrate their usefulness. Try to reframe a caregiver's criticisms of an idea so that the criticisms are actually in agreement with the basic concept being presented. For example, it is common for caregivers to argue that the idea of increasing pleasant events to enhance mood is not relevant to them because they have no time for such things if they are going to take good care of their family members. The coach can then respond that it is precisely because caregiving normally leaves them with little time for pleasant events that it becomes essential for them to actively create some. If they do not do so, they will eventually become too stressed to continue delivering good care to the patient, and both of them will be miserable.

12. Coaches should expect to encounter some nonreceptiveness to completing exercises. The exercises do not involve a great deal of time, but they do require the caregivers to build in some new habits (e.g., making mood and event ratings each night, counting occurrences of pinpointed problem

behaviors, etc.). Some people are not receptive to completing the exercises, particularly when they are experiencing the time constraints common to caregivers. Coaches should empathize with the severe restrictions that the caregivers have on their time, but it may also be necessary for the coaches to gently “nudge” caregivers to complete a sufficient amount of the activities for them to benefit from this program. Coaches should remember, however, that partial completion of assignments may provide enough information to identify patterns of mood, activities, and problem behaviors. Thus, if the caregiver is collecting enough information to establish such patterns, do not push for more.

Coaches should also briefly re-explain the rationale for the assignments (e.g., build in new habits and skills which take day-to-day practice). In this case, the coach can emphasize that if the caregiver just completes the video and the phone call, they are really not doing enough to develop the skills because these two components take less than two hours in a 168 hour week, which is 1% of the caregiver’s week. Emphasize the need for the information the assignments provide and assure the caregivers that it is not just “busy work.”

In addition, work with the caregiver to determine what obstacles prevented the completion of the exercises. Help caregivers work out a specific routine that makes the exercises as painless as possible (e.g., where will the forms be kept, what time of the day will they be completed, etc.). Judith Beck (1995) provides tips for including exercises in an individual’s daily routine:

- A. Link assignment to another activity (e.g., bedtime).
- B. Put post-it reminders on bathroom mirror or refrigerator.
- C. Ask the individual how she remembers other things, like taking medications. Then use the same reminder for the exercises.

If a caregiver does not complete the exercises, coaches need to help prevent a caregiver from labeling herself a failure. Complete the exercises on the telephone, and be sure that both the coach and the caregiver write the information down on the appropriate worksheets. It may not be possible to complete the exercises in their entirety, but attempt to get as much information as possible. Emphasize to the caregiver that the exercises can still be useful even if they are done on the telephone.

Of course, a person who chronically does not complete the assignments may be expressing a need for services other than, or in addition to, those offered by this program. The treatment team may recommend discussing this possibility with the caregiver and, if necessary, assist her with a referral to her local Area Agency on Aging or Alzheimer’s Association chapter.

13. When reviewing pleasant activities with a caregiver, the coach should maintain a balance between emphasizing the importance of increasing pleasant events for the person with dementia AND increasing pleasant events for the caregiver.

14. One of the goals of this program is to increase caregivers’ positive self-statements. Thus, when a caregiver is developing an action plan, coaches should try to incorporate a positive cognitive reminder into this plan. For example, “Remind myself that it is important to try, even if it doesn’t work right away,” might be added to the plan as a cognitive reframe.

15. In the sessions where activity scheduling is introduced, the coach should encourage caregivers to

list some form of physical activity on both the caregiver's and the patient's list. There is clear empirical evidence that exercise is an important part of treating and preventing depression. In addition, we know that most caregivers and patients get far less physical activity than what is helpful for them. The physical activity does not have to be overwhelming, but could be something as little as walking the patient to the mailbox, around the yard, or down the street to the next block.

16. When creating lists of activities with a caregiver, the coach should make sure that the list is not completely comprised of all the things that the caregiver and patient are already doing frequently. Coaches should be looking to help caregivers add and change their activity list, so that they include things caregivers used to do, but have stopped doing or only do rarely.

17. From the start of this program, coaches should help caregivers maintain gains past termination of this program. This can be done in ways discussed below.

A. Prepare caregiver for setbacks and difficulties. Sometimes caregivers expect that they'll make steady progress and when they have a setback, they begin to beat themselves up. It's very important for them to know that making errors or having setbacks is part of developing any skill or making any change. To give examples, think of the championship ice skater who falls on the ice in front of a large audience. Yet, they just get up, continue, and learn from the fall. Another example is that many people who successfully stop smoking have tried and failed several times before finally quitting.

B. Assist the caregiver to take credit for her efforts and progress. Listen for instances in which the caregiver is attributing her success to external factors (e.g., the coach, the program, or the workbook), and work with her to help her attribute her success to her own actions. To the extent that the caregiver attributes her progress to her own work and perseverance, she is less likely to feel dependent on an external source and more likely to maintain her gains beyond the end of the project (Bandura, 1986). The coach can build this self-attributional process in the caregiver by asking such questions as, "How were you able to carry out the assignment? How did it make you feel? How was your present success different from earlier efforts that didn't go as well? What does this change mean about you as a person?" (Lewinsohn, 1987). The following example, based on dialogue by J. Beck (1995, p. 272), demonstrates a telephone coach (TC) assisting the caregiver (CG) to attribute mood improvement to her own efforts:

TC: Why do you think you feel better this week?

CG: You and the video helped me.

TC: Sure, the video and I may have helped you understand this new skill, but who was it who really changed your behavior?

CG: Well, I guess I did it.

TC: How much do you believe that *you're* the one who deserves the credit?

For those cases in which the caregiver attributes her better mood to an external event (e.g., the concert she attended), or to a medicine, the coach may agree that such factors may have played an important part, but then ask about changes in the *caregiver's* behavior that

contributed to the improvement – for example, she made the choice to attend the concert (Beck, 1995).

C. In terms of developing an action plan, it will be important for the coach to frequently emphasize the overall concept of changing a problem behavior by altering the triggers specific to the family member's behavior problem instead of offering suggestions and advice for a specific problem behavior. In other words, after introducing the six steps for working on a behavior problem, refer back to these six steps. If the caregiver understands the link between triggers and her family member's behavior problem, than it is more likely that she will be successful in addressing problem behaviors that come up after her involvement in this program is over. She will have the skills necessary to identify triggers to new behavior problems and develop an action plan that changes the triggers to that problem. Alternatively, if a caregiver relies on a coach to provide suggestions for a given problem behaviors, it is unlikely that she will be able to independently make changes to decrease future problem behaviors.

Telephone Session Objectives and Content

This project's telephone sessions have four primary objectives: (1) to improve caregiver mood through demonstrating the relationship between mood and pleasant events and by assisting the caregiver to develop the skill of increasing pleasant events for her and the patient; (2) to substantially reduce at least one problem behavior through the use of behavioral management skills; (3) to reduce caregiver stress through development of basic relaxation skills; and (4) to increase the caregivers' sense of self-efficacy through development of the skills described in objectives one, two, and three.

The content of telephone sessions one through twelve is summarized as follows:

- Session 1: Information about dementia and Alzheimer's Disease; how providing care can affect the caregiver; some "Basic Rights" of caregivers; completion of an exercise listing caregiver and family member's pleasant events.
- Session 2: Depression and its effect on patients and caregivers; how daily activities can help reduce or prevent depression; how to get started increasing pleasant daily activities for caregiver and family member; finding specific activities to fight depression.
- Session 3: Attitudes or reactions that can get in the way of doing pleasant activities; communicating with family members so that activities are fun and not an extra burden; how keeping track of things on paper can help a caregiver feel more in control.
- Session 4: How a caregiver can find time for herself; ways to ask for help from others; communication tips with friends and family; beginning to look at behavior problems.
- Session 5: Learning more about problem behaviors; finding the "triggers" for problems in your caregiving situation; continuing to plan pleasant activities.
- Session 6: Developing an action plan to change behavior; examples of managing

- specific problems; reducing problems by improved communication.
- Session 7: Specific ways to manage difficult behaviors; how to handle problems in activities of daily living.
- Session 8: Danger signals and how to recognize early signs of stress; an introduction to the skill of relaxation and why it is so important for caregivers.
- Session 9: Using relaxation in stressful caregiving situations; solving problems related to relaxation.
- Session 10: Home safety; looking to the future: legal and financial issues; summary of video program; what's next.
- Session 11: Problem-solving; maintaining gains.
- Session 12: Problem-solving; review of strengths and progress, maintaining gains.

Screening and Assessment Interviews

Screening of Prospective Caregiver Participants

A telephone screening interview of prospective study participants will determine their interest and eligibility. During a brief conversation with the caregiver, the interviewer will explain the nature of the project, including the goal of skill-building. The interviewer will attempt to learn what the caregiver hopes to gain from the project. If the individual's expectations do not match the project goals, the interviewer will assist the caregiver to find a more appropriate service. It is our experience that individuals who primarily want something the project does not offer will eventually drop out, even if they are persuaded to "give the program a try."

During the screening, the interviewer will administer a series of questions assessing caregiver and patient characteristics (to determine whether both individuals meet inclusion criteria), the Revised Memory and Behavior Problems Checklist (RMBPC; Teri et al., 1992), the Center for Epidemiologic Studies Depression Scale (CES-D) Boston Short Form (Kohout, Berkman, Evans, & Cornoni-Huntley, 1993), the Hearing Handicap Inventory for the Elderly (HHIE; Ventry & Weinstein, 1982) the Low Vision Quality of Life scale (LVQOL; Wolffsohn & Cochrane, 2000), and the Short Portable Mental Status Questionnaire (SPMSQ; Roccaforte, Burke, Bayer, & Wengel, 1994). The SPMSQ helps identify caregivers who may not be able to understand the material presented in the treatment or control conditions. Any questions regarding a caregiver's eligibility should be discussed with the Principal Investigator.

Assessment Interviews

Participants in both the control and treatment groups will complete four assessment interviews over the course of their involvement in the Dementia Caregiving Skills Program. They will complete an assessment interview prior to starting either program as well as follow-up assessment interviews

upon completion of the program, at three months post-completion, and again at six months following the 14-week program. These assessment interviews are comprised of two parts: questionnaires for the caregiver to complete independently and questionnaires to be completed on the telephone with a staff member. The caregiver completes the at-home questionnaires at her convenience and mails them in upon completion. An appointment is scheduled for the telephone portion of the assessment interview. The telephone portion takes approximately 45 to 90 minutes to administer and complete.

Coaches Qualifications and Training

The telephone sessions are led by the Project Coordinator (a licensed clinical psychologist), and graduate students who are enrolled in a doctoral clinical psychology program.

Project staff should read at least some of the suggested readings provided at the end of this introduction (page 19) in order to become more familiar with the basic issues of caregiving, Alzheimer's Disease, various dementias, and the theories and practice of the main interventions associated with this program. Reading The 36-Hour Day (Mace & Robins, 1999) is a good way for coaches to become familiar with the basic issues in dementia caregiving. In addition, telephone coaches need to become familiar with the basic principles of applied behavioral analyses and the six steps that caregivers are taught to change a behavior problem (name the problem, keep track of the problem, find the triggers, change the triggers, keep track of findings, and continue until there is improvement). In addition, project staff attend weekly clinical meetings with the Principal Investigator and Project Coordinator who provide supervision, training, and monitoring of caregivers. Supervision includes monitoring safety issues for these caregivers and their family member, and discussion of strategies for solving problems either anticipated or encountered in the telephone sessions with caregivers in either condition.

In terms of managing behavioral problems, the best overall references for telephone coaches is Robinson, Spencer, and White's (1992) guide, Understanding Difficult Behaviors. In addition, each coach should have a binder in her office containing Burgio's behavioral prescriptions from the Alabama REACH site. These materials can be used as resources when coaches are faced with new and unfamiliar behavior problems.

Adherence/Competence will be assessed by nonaffiliated raters who will listen to selected audiotapes of all coaches; these raters are skilled in the performance and supervision of these interventions. The adherence/competence rating forms for this project were patterned after the recommendations of Waltz et al. (1993).

Readings and Other Resources for Telephone Coaches (*Highly recommended)

- Alzheimer's Association of St. Louis. (1999). *Basic care guide: A resource for caregivers*. St. Louis, MO: Alzheimer's Association of St. Louis.
- Bandura, A. (1986). *Social foundations of thoughts and action: A social cognitive theory*. Englewood Cliffs, NJ: Prentice-Hall.
- Bandura, A. (1997). *Self-efficacy: The exercise of control*. New York: W. H. Freeman and Company.
- Beck, J. S. (1995). *Cognitive therapy, basics and beyond*. New York: The Guilford Press.
- Benson, H. (1984). *Beyond the relaxation response*. New York: Berkley Publishing Group.
- Benson, H. (1975). *The relaxation response*. New York: William Morrow and Company.
- Cohen, C. A., Gold, D. P., Shulman, K. I., Wortley, J. T., McDonald, G., & Wargon, M. (1993). Factors determining the decision to institutionalize dementing individuals: a prospective study. *The Gerontologist*, 33, (6), 714-720.
- Folstein, M., Folstein, A., & McHugh, P., (1975). Mini-Mental State: A practical method for grading the cognitive state of patients for the clinician. *Journal of Psychiatric Research*, 12, 189-198.
- Gallagher-Thompson, D., Ossinalde, C., & Thompson, L. W. (1996). *Coping with caregiving: A class for family caregivers*. Palo Alto, CA: Department of Veterans Affairs Medical Center & Stanford University School of Medicine.
- Gallagher-Thompson, D., Rose, J., Florsheim, M., Gantz, F., Jacome, P., Del Meastro, S., Peters, L., Arguello, D., Johnson, C., Moorehead, R. S., Polich, T. M., Chesney, M., & Thompson, L. W. (1992a). *Controlling Your Frustration: A Class for Caregivers: Leaders Manual*. Palo Alto, CA: Department of Veterans Affairs Medical Center.
- Gallagher-Thompson, D., Rose, J., Florsheim, M., Gantz, F., Jacome, P., Del Meastro, S., Peters, L., Arguello, D., Johnson, C., Moorehead, R. S., Polich, T. M., Chesney, M., & Thompson, L. W. (1992b). *Controlling Your Frustration: A Class for Caregivers: Participant Workbook*. Palo Alto, CA: Department of Veterans Affairs Medical Center.
- Gant, J. R., Steffen, A. M., Silberbogen, A. K., & Gallagher-Thompson, D. (2001). *The Dementia Caregiving Skills Program: Reducing Distress and Enjoying Time with your Family Member. Coach Manual*. St. Louis, MO: University of Missouri – St. Louis.
- Jacobson, N.S., Dobson, K. S., Truax, P. A., Addis, M. E., Koerner, K., Gollan, J. K., Gortner, E., & Prince, S. E. (1996). A component analysis of cognitive-behavioral treatment for depression. *Journal of Consulting and Clinical Psychology*, 64, 295-304.
- Kiecolt-Glaser, J. K., & Glaser, R. (2001). Stress and immunity: Age enhances the risks. *Current Directions in Psychological Science*, 10, 18-21.

- Kohout, F. J., Berkman, L. F., Evans, D. A., & Cornoni-Huntley, J. (1993). Two shorter forms of the CES-D depression symptoms index. *Journal of Aging and Health, 5*, 179-193.
- Lewinsohn, P. (1987). *Facilitating treatment adherence*. New York: Plenum Press.
- Lewinsohn, P., Munoz, R., Youngren, M., & Zeiss, A. (1992). *Control your depression (revised edition)*. New York: Simon & Schuster..
- *Mace, L., & Robins, P. V. (1999). *The 36-hour day*. Third edition. Baltimore, MD: The Johns Hopkins University Press.
- *McCurry, S. M., Logsdon, R. G., & Teri, L. (1996). Behavioral treatment of sleep disturbance in elderly dementia caregivers. *Clinical Gerontologist, 17*, 35-50.
- *Persons, J. B., Davidson, J., & Tompkins, M. A. (2001). *Essential components of cognitive-behavior therapy for depression*. Washington, D.C.: American Psychological Association.
- Pinkston, E. M., & Linsk, N. L. (1984). Behavioral family intervention with the impaired elderly. *The Gerontologist, 24*, 576-583.
- Pinkston, E. M., Linsk, N. L., & Young, R. N. (1988). Home-based behavioral family treatment of the impaired elderly. *Behavior Therapy, 19*, 331-344.
- *Robinson, A., Spencer, B., & White, L. (1992). *Understanding difficult behaviors*. Ypsilanti, MI: Alzheimer's Education Program, Eastern Michigan University.
- Roccaforte, W. H., Burke, W. J., Bayer, B. L., & Wengel, S. (1994). Reliability and validity of the Short Portable Mental Status Questionnaire administered by telephone. *Journal of Geriatric Psychiatry and Neurology, 7*, 33-38.
- *Schulz, R., O'Brien, A. T., Bookwala, J., & Fleissner, K. (1995). Psychiatric and physical morbidity effects of dementia caregiving: prevalence, correlates, and causes. *The Gerontologist, 35*, 771-791.
- Schwartz, B., & Reisberg, D. (1991). *Learning and memory*. First edition. New York: W.W. Norton & Company, Inc.
- *Steffen, A. M. (2000). Anger management for dementia caregivers: A preliminary study using video and telephone interventions. *Behavior Therapy, 31*, 281-299.
- Steffen, A. M., Gant, J. R., Coon, D. W., Gallagher-Thompson, D., Thompson, L., Burgio, L., & Stevens, A. (2001a). *The Dementia Caregiving Skills Program: Reducing Distress and Enjoying Time with your Family Member. Video Series and Participant Manual*. St. Louis, MO: University of Missouri – St. Louis.
- Steffen, A. M., McKibbin, C., Zeiss, A. M., Gallagher-Thompson, D., & Bandura, A. (2002).

- The revised scale for caregiving self-efficacy: Reliability and validity studies. *Journal of Gerontology*, 57B, P74-P86.
- *Teri, L. (1990). *Managing and Understanding Behavior Problems in Alzheimer's Disease and Related Disorders*, two-video set containing 10 modules. Seattle: University of Washington.
- *Teri, L., & Logsdon, R. (2000). Assessment and management of behavioral disturbances in Alzheimer Disease. *Comprehensive Therapy*, 26, 169-175.
- Teri, L., Truaz, P., Logsdon, R., Uomoto, J., Zarit, S., & Vitaliano, P. P. (1992). Assessment of behavioral problems in dementia: The revised memory and behavior problems checklist. *Psychology and Aging*, 7, 622-631.
- *Teri, L., & Uomoto, J. M. (1991). Reducing excess disability in dementia patients: training caregivers to manage patient depression. *Clinical Gerontologist*, 10, 49-63.
- Teri, L., Logsdon, R., Weiner, M., Trimmer, C., Thal, L., Whall, A., Peskind, E. (1998). Treatment for agitation in dementia patients: A behavior management approach. *Psychotherapy*, 35, 436-443.
- Thompson, L., Gallagher, D., & Lovett, S. (1992). *Increasing life satisfaction class: Leaders' and participants' manuals (revised versions)*. Palo Alto, CA: Dept. of Veterans Affairs Medical Center & Stanford University School of Medicine.
- Ventry, I. M., Weinstein, B. E. (1982). The Hearing Handicap Inventory for the elderly: a new tool. *Ear and Hearing*, 1092, 128-134.
- Waltz, J., Addis, M. E., Koerner, K., & Jacobson, N. S. (1993). Testing the integrity of a psychotherapy protocol: Assessment of adherence and competence. *Journal of Consulting and Clinical Psychology*, 61, 620-630.
- Wolffsohn, J. S., & Cochrane, A. L. (2000). Design of the Low Vision Quality-of-Life Questionnaire (LVQOL) and measuring the outcome of low-vision rehabilitation. *American Journal of Ophthalmology*, 130, 793-802.
- *Zarit, S. H. (1996). Interventions with family caregivers. In S. H. Zarit, & B. G. Knight (Eds.), *A guide to psychotherapy and aging, effective clinical interventions in a life-stage context* (pp. 139-159.) Washington, D.C.: American Psychological Association.
- Zeiss, A.M., & Steffen, A. M. (1996). Treatment issues with elderly clients. *Cognitive and Behavioral Practice*, 3, 371-389.