Appendix H.
Coping With Caregiving

Training Issues

This manual describes the methods for teaching family caregivers the basic steps for learning to relax, to control their negative thoughts, and to act assertively and increase pleasant events when necessary.

Although we provide instructors with a fairly detailed text, we believe that a strong background in both cognitive-behavioral therapy and small group dynamics is helpful to successfully guide stressed caregivers through these procedures. If you do not have such training, leading this class successfully may be difficult. We recommend that you contact any one of the several agencies listed on the inside cover to inquire about training possibilities.

Ideally, class leaders will have received specific training in this psycho-educational program prior to their taking on the leader's role. Completing the following sequence would accomplish this goal:

1. Reading one or more books on cognitive/behavioral therapy, since this is the theoretical framework from which the class was developed (specific references will be found at the end of this section);
2. Being a “participant observer” in one complete class series, in order to experience the class first-hand (We will elaborate further on the role of the participant observer later in the introduction.);
3. Being a co-leader, along with a more experienced leader, if possible, in order to complete the process of becoming an independent leader.

While this may seem to be a lengthy process, it is one we have followed in the past and which trainees have found to be extremely helpful in their development.

Some interested and qualified potential instructors may not be able to go through this entire sequence of training. Our experience has shown that instructors must have at least a demonstrated ability to teach material designed to help people reduce their emotional distress. Potential leaders who have limited experience dealing with emotionally distressed people, and/or who are uncomfortable assuming a strong teaching role, will not be good leaders for this class. This class requires leaders who can both empathize with the stresses of caring for a frail elder, and who are solid teachers, able to clearly convey complex information.
Suggested Readings on Cognitive/Behavioral Therapy and Its Use With Older Adults


Suggested Readings on Psychoeducational Treatment for Distress

Psychoeducational programs have been developed to treat a range of problems, including:

**Depression:**

**Low life satisfaction in elders:**
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Problem Drinking:

Eating Disorders:

Practical Issues Regarding Class Composition and Implementation

In selecting class participants, we recommend that leaders screen all potential participants. This will enable the leaders to refer individuals in need of more intensive treatment to individual counseling and other appropriate forms of treatment. This class format is not appropriate for caregivers who are significantly depressed or who are suffering from any other serious mental health problem. Caregivers who are abusing their frail relatives need to be seen for individual help because their problems are not amenable to the small group format of this class. Note that although most caregivers suffer from stress, their stress is not so severe that they would not be appropriate candidates for these classes. However, when in doubt, we recommend that you err on the side of caution and provide more intensive treatment.

Screening will generally consist of a face-to-face interview inquiring about mental status, level and causes of stress, coping behaviors, available supports, and other significant problems in the person's life. We also use self-report questionnaires, to determine the level of stress. We usually re-administer such measures at the end of the class, to help us evaluate participants' progress.

Note that the class is intended to run for ten weeks. When selecting a site for the classes, please be sure to check that it will be available for the entire class series. Each class is designed to last for two hours and includes a ten-minute break, during which time refreshments are served and socializing is encouraged. In general, classes start with a brief presentation of didactic material, followed by a workshop in which participants share their perceptions and reactions to the material presented. The aim is to maximize the material's relevance to each participant's own personal situation.

To assist in this process, two trained persons co-lead all the classes. In order to deal with any problems that may arise, it is preferable that at least one of the class leaders be a mental health professional. The two co-leaders need to be able to confer regularly to plan for each upcoming class.
We also recommend that the class leaders include two “participant-observers” in each class series. Participant-observers are frequently persons in training to become class leaders. They function as participants by doing the same homework as the other class members, and by sharing their personal experiences. They also assist the leaders in the running of the class. For example, some class members may have more difficulty than others in understanding the materials. The participant-observers can help these class members individually, in a more personalized manner than the leaders are often able to do. In our experience, including one or two participant-observers helps the class run smoothly. Acting as a participant-observer also provides an excellent training for being a class leader in the future.

The class should consist of between six and ten caregivers. Managing the class can be difficult if there are fewer than six, or more than ten participants. We also strongly recommend that class leaders praise all homework completed between class sessions to reinforce the participants’ continued effort.

We provide a suggested time allotment for each component of the class in parentheses after the heading of each section, such as RELAXATION RATINGS AND PRACTICE EXERCISE 910 min.). Using this time allotment as a guide will assure that the leaders cover all of the material in each class. Remember that these times are only a suggested schedule, and you should not use them as absolute time limits. As long as you cover all of the material, the dynamics of the group should determine the pace of the class. When two instructors teach the class, the instructors need to agree ahead of time on the material each will present.

Class participants will come from all walks of life, with different reading and language skills. Accommodating the special needs and backgrounds of the participants in each class is very important. Paying attention to these factors is especially important in the first few classes, in order to ensure that no participant feels left out or put down. The differences in participants’ language skills have been especially apparent in the filling out of the various homework forms. Explain slowly and patiently how to fill out these forms and check whether all participants are completing them correctly. This is particularly important each time you introduce a new form.
Instructors will also need to convince the participants of the value of filing out the various forms included in each session. Filling out forms to record one's thoughts and feelings is not a common experience for many older people. You will need to explain several times that by filling out the forms the participants will be able to see their progress in performing the exercises over time.

You also need to reassure participants that you will not be judging their homework, particularly not in terms of their ability to write or spell correctly. Remind them that the goal of the homework is to practice what they have learned between classes.

The most important element of a successful class is a cooperative relationship between the leaders and the students. It is thus essential that leaders frequently seek feedback from the class, and make the necessary changes in presenting the material to ensure that all members understand what is being taught, and have an opportunity to overcome any hesitation they might have toward trying new techniques.

We recommend that you arrive at least one-half hour before class, so that the participants will have time to talk with you alone. Among Hispanic families, conversing with the instructor is very important. It also assures that the instructor and the participants will know each other better, and, in turn, helps the class be more successful.

Occasionally, leaders may encounter someone who is very uncooperative with these methods and who is actually disruptive to the class. It's important to speak to this person individually as soon as possible, to see if you can solve any problems, so that the person may remain in the class. If not, then an appropriate referral should be made.

Referrals

For a variety of reasons, you may need to direct class participants to resources in the community outside of the course itself. Leaders may encounter caregivers who express an interest in the course, but who may be unable to attend. Also, you may find course participants whose needs exceed the offerings of the course. While we acknowledge the need for flexibility, delivering the content of the course to all participants as intended is important. You will be better able to adhere to the course outline if you know that a participant's additional care needs may be able to be met outside the class. Therefore, you should be prepared to make referrals for concerns the participants may bring up that you cannot address in the class. Familiarizing yourself with information and referral sources in your community is essential. We recommend that you locate, or develop, accurate local health and social services directories to give to participants.
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In California we are fortunate to be able to offer families a range of resources. The State of California underwrites in part nine Alzheimer’s Diagnostic and Treatment Centers. Additionally, the Alzheimer’s Association, a voluntary health organization, serves much of California and provides family support groups, dementia-specific information and referral, and educational materials and programs. Some of these materials and services are available in Spanish.

To contact the Greater San Francisco Bay Area Chapter of the Alzheimer’s Association, call:


This chapter can refer you to other chapters, both within California and in other states.

To contact the national office of the Alzheimer’s Association, in Chicago, Illinois, call:

- 1(800) 272-3900
Research, Evaluation and Collaboration Issues

We have developed and modified this class over a three-year period, and have endeavored to make it culturally relevant to Hispanic caregivers. Our evaluation data indicate that we were very successful overall, with both men and women caregivers, and with persons from a variety of cultural backgrounds. Thus we are excited about the continued usefulness of this approach and hope that your experiences are as positive as ours have been. We welcome your comments! Please feel free to write or call us at the VA Palo Alto Healthcare System Mail Code 182C/MP, 795 Willow Road, Menlo Park, CA 94025-0000, (650) 617-2774.

Finally, we continue to evaluate our program and to research Hispanic families caring for a frail elder relative. In this context, we are aware of many complex research issues and would be pleased to share our information with other interested investigators. We would also like to collaborate with other persons and agencies conducting similar research. Such collaboration could markedly increase the size of our sample population, and could lead to more significant research conclusions. Please do not hesitate to contact Dr. Dolores Gallagher-Thompson to discuss any ideas you might have for future collaborations.