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The Peaceful Mind Manual: A Protocol for Treating Anxiety in Persons with Dementia

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Abstract

Anxiety disorders are highly prevalent among individuals with dementia and have a significant negative impact on their lives. Peaceful Mind is a form of Cognitive-Behavioral Therapy for anxiety in persons with dementia. The Peaceful Mind manual was developed, piloted and modified over 2 years. In an open trial and a small randomized, controlled trial, it decreased anxiety and caregiver distress. The treatment meets the unique needs of individuals with dementia by emphasizing behavioral rather than cognitive interventions, slowing the pace, limiting the material to be learned, increasing repetition and practice, using cues to stimulate memory, including a friend or family member in treatment as a coach, and providing sessions in the home. The manual presented here includes modules that teach specific skills, including awareness, breathing, calming self-statements, increasing activity, and sleep management, as well as general suggestions for treatment delivery.

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Anxiety is a significant problem for individuals with dementia, with prevalence estimated to be 35% (Seignourel, Kunik, Snow, Wilson & Stanley, 2008). Anxiety coexistent with dementia is associated with increased behavioral problems and limitations in activities of daily living (Teri et al., 1999), decreased independence (Porter et al., 2003), and increased risk of nursing-home placement (Gibbons et al., 2002). Despite the high prevalence and significant negative impact that coexistent anxiety poses for these individuals, no manualized treatment protocols exist to guide the treatment of anxiety in people with dementia. Cognitive behavior therapy (CBT) is the psychosocial treatment of choice for anxiety disorders among younger adults (Barlow, 2004), and CBT is effective for the treatment of anxiety in older adults without cognitive impairment (Thorp et al., 2009). Because CBT's effectiveness may be less dependent on the presence of abstract reasoning abilities than less structured forms of therapy (Doubleday, King & Papageorgiou, 2002), this approach may be an appropriate choice for patients with dementia. Case reports support the use of CBT for anxiety and depression in persons with dementia (e.g., Bird & Blair, 2010; Koder, 1998; Kraus et al., 2008); and behavioral interventions are efficacious for depression in persons with dementia, especially when caregivers are involved (e.g., Teri et al., 1997). The potential effectiveness of CBT for anxiety in persons with dementia has even prompted national recommendations to consider this approach in this population (National Institute for Health and Clinical Excellence, Social Care Institute for Excellence, 2006). For these reasons, we developed Peaceful Mind, a cognitive behavioral treatment for anxiety in the presence of dementia.

Peaceful Mind was derived from evidence-based cognitive behavioral interventions for anxiety and depression in cognitively intact older adults (Quijano et al., 2007; Stanley, et al., 2009) and behavioral interventions to reduce depression in dementia (Teri et al., 2005). The treatment was modified to meet the unique needs of clients with dementia (Snow, et al., 2006), including emphasizing behavioral rather than cognitive interventions, slowing the pace, limiting the material to be learned, increasing repetition and practice, using cues to stimulate memory, and including a friend or family member in treatment as a coach.

The Peaceful Mind manual was developed, piloted and modified over 2 years, using a case series of seven clients. During treatment development, feedback was sought from experts in the field, clinicians, clinical supervisors, and clients. The feasibility and preliminary outcomes of the Peaceful Mind manual were evaluated in an open trial ($\underline{n} = 9$; Paukert et al., 2010) and followed up with a small, randomized, controlled trial ($\underline{n} = 32$; Stanley et al., 2012). In both trials, most persons with dementia participated in the intervention for an average of nine sessions over 3 months, which is remarkable considering that a majority were diagnosed with dementia of moderate severity. Persons with dementia and/or caregivers were able to complete home practice assignments, and caregivers reported high satisfaction and improved communication. In the randomized controlled trial, after 3 months of treatment, persons with dementia who received the intervention were rated by clinicians as less anxious than those who completed usual care, and they rated themselves as having higher quality of life. Additionally, caregivers who participated in the intervention reported less distress related to their loved ones' anxiety.

INTRODUCTION

The procedures outlined in this manual are designed to treat clinically significant anxiety (no specific anxiety disorder diagnosis is necessary) in adults age 50 and over with mild-to-moderate dementia (e.g., Clinical Dementia Rating scores of .5 to 2; Morris, 1993), but they may also be useful for older adults with other forms of cognitive impairment. Clients should have the capacity to consent to treatment, be active participants in therapy sessions for at least 20 minutes at a time, and not acutely psychotic, suicidal, or homicidal. The cognitive

abilities in those with dementia of mild to moderate severity are highly variable. For this reason, this treatment is highly flexible and potential adjustments for differing levels of cognitive impairment are reviewed throughout the manual. Procedures are intended for use by master's-level clinicians with training in the theory and practice of CBT. A thorough assessment of the client and collateral's presenting problems (including suicide risk and depression) and desires for treatment should be completed prior to beginning treatment. Although the treatment targets anxiety, methods overlap with treatments for other psychological problems (e.g., depression, sleep difficulties), which is important, given the large overlap between anxiety, depression, sleep problems and physical health concerns in the older-adult population (Wolitzky-Taylor et al., 2010). Thus, skills may be applied to other problems.

Home Based

To lessen transportation barriers and increase generalizability of learned skills, Peaceful Mind is designed to be delivered in the client's home, if feasible. As a home-delivered intervention, sessions may be interrupted by multiple distractions. The clinician should address these issues early in the course of the program and encourage strategies to avoid interruptions (e.g., turning phones off, scheduling sessions during convenient times or at alternate locations).

Role of the Collateral

Ideally, a collateral is present during each session to learn the skills and serve as a coach to help the client practice between sessions. Collaterals are defined as family members, spouses, or friends who have at least 8 hours per week of contact with the client. Telephone follow-up occurs between sessions with both the collateral and client.

There is flexibility in the role of the collateral. The clinician works with the dyad to determine the collateral's level of involvement, based on both the client and collateral's levels of skill and understanding, collateral availability, and client comfort. The plan for the role of the collateral in coaching each week's daily practice is discussed during the in-person session and recorded in the workbooks. There are several options for how a collateral may work with the client. For example, the collateral can (1) initiate the activity and complete it with the client, (2) remind the client to do the activity, or (3) check on completion of the activity. The clinician should be flexible and help the dyad consider multiple options for working together to meet the needs of different clients' varying levels of cognitive functioning as well as the needs of the client-collateral relationship itself. The nature and intensity of collateral involvement may fluctuate over the course of treatment, depending on the type of skill and duration of prior practice, the availability of the collateral, and the ability of the client to practice skills between sessions without collateral assistance.

The collateral's role in treatment is crucial, and his/her efforts are supported by the clinician. A collateral may become frustrated with a client, as is common among caregivers of individuals with dementia. It is important to monitor and discuss feelings of frustration and disappointment with both the client and the collateral. Clinician-client interactions can be used to model appropriate interactions for the collateral. For example, if the collateral is too overbearing, the clinician may give the client more encouragement to express opinions and to become more active in the session/activity.

More than one collateral may be involved (see Robinson et al., 2011, for case examples). In these cases, the clinician works with these individuals to delineate the roles for each person, taking into account the client's preferences for collateral involvement. It is also important to establish a system for communicating between collaterals so that they are in agreement

about their respective duties, maintain communication about the client's progress and consistency in their approaches, and keep in mind the client's goals.

Despite the involvement of collaterals, the person with dementia is the identified client, and as such, the clinician always directs initial instructions toward him or her. This is important for rapport and for increasing the client's feelings of involvement in treatment.

Client and Collateral Workbooks

The client and collateral receive workbooks to help them learn and use the skills. Handouts are added to the workbooks as treatment progresses to avoid overwhelming the client at the outset of treatment. Examples of handouts will be given, but these handouts may be further simplified as necessary for to meet the cognitive needs of the client. This may include significantly reducing the information on handouts. As older adults are more likely to have difficulties with vision, it is helpful if the print on handouts is large.

Overall Treatment Structure

Peaceful Mind is intended to be provided over a 6-month period. The first 3 months of treatment consist of 9 to 12 weekly in-person sessions in the client's home, each followed by a brief telephone check-in to review and reinforce skill practice, help solve any problems, provide encouragement, reinforce the rationale for practice, and answer questions. The duration of in-person sessions is 30 to 60 minutes, depending on the needs and attention span of the client and collateral. Subsequent telephone follow-up appointments, weekly for 4 weeks and biweekly for 8 more weeks, are conducted over the second 3 months of treatment, to encourage continued use of skills.

The manual includes modules that teach specific skills, including awareness, breathing, coping self-statements, increasing activity, and sleep management. There is flexibility in the selection of modules and the order of skill learning. The clinician decides with input from the client and collateral which skills best fit the client's symptoms and abilities. It will likely take more than one session for clients to master a skill. The Introduction and Module A (Awareness) generally can be completed together in the first session. In most cases, Module B (Breathing Changes) will also be completed in the first few sessions. Subsequent modules may be conducted in any order. Individual modules may be focused on for multiple sessions if necessary for the client to learn the skill or a new module may be introduced each session for clients who learn more quickly.

Clinicians should begin preparing the clients and collaterals for transition from skill learning to telephone maintenance about two thirds of the way through the treatment by reminding them about the number of sessions remaining and when they will occur. If it appears that the client and collateral have learned the tools from the treatment and are primarily working on implementing and maintaining the changes, the last few sessions may be more widely spaced in preparation for termination. The Termination/Transition session should occur at the end of the active-treatment phase (12 weeks).

Individual Session Structure

The clinician may need to slow the pace of sessions and repeat key points more often than is typical in CBT with clients who do not have dementia. One particularly effective way to do this is with the "sound bite" approach: summarizing a key point with a short phrase (5-10 words); repeating that exact phrase and asking the client to repeat that phrase at multiple, spaced repetitions throughout a session; and using this exact phrase whenever repeating that key point throughout the sessions. This approach capitalizes upon the abilities of most

persons with dementia to learn small amounts of information if there are enough opportunities for rehearsal (see spaced retrieval [SR] section below; Camp, 2006).

Sessions begin with a reminder of who the clinician is and why he or she is meeting with the client and his/her collateral. It may take weeks before the clinician is a familiar addition to the client's routine. After these introductions/reminders, the clinician should provide a printed agenda for the session, which includes the clinician's name, name and purpose of the program, date, session number, and goals of the meeting. This agenda is referred to throughout the session to keep the session on-track (Figure 1). The clinician then reviews home practice and prior skills. Next, if a new skill is being introduced, it is taught. The clinician should regularly query the client to make sure he/she understands the information being presented and observe the client and collateral practicing the new skill.

Lastly, the clinician guides the client and collateral in formulating a plan for practicing the skills over the next week. The importance of daily practice should be conveyed to the client and collateral. The role of the collateral(s) in coaching the week's daily practice is discussed and recorded on forms in both the client's and collateral's workbooks. The level of coaching in daily practice will depend on the needs and desires of the client. For moderately cognitively impaired clients, coaching may involve the collateral engaging in the homework assignment alongside the client. For mildly cognitively impaired clients, coaching may just include reminding the client of the homework or verifying that it was performed. Both the collateral and client should practice the coaching interactions during the session (e.g., how the collateral will initiate the daily practice in a way that is not offensive to the client; how the dyad will work together to practice). Depending on living arrangements, practice sessions between the client and collateral may be in-person and/or via telephone. It is beneficial to end each session by reinforcing the client's and collateral's efforts.

Telephone Midweek Follow-up

Clinicians should speak privately with both the collateral and the client between sessions. After the first session, clinicians specifically address the following during the mid-week telephone call with the collateral: 1) these calls as an opportunity for them to ask questions or voice frustrations or difficulties they may be having with the treatment or with the client's participation in the treatment, 2) the importance of their role in the success of the intervention, and 3) optimism about the treatment program and their role in its success. In all midweek follow-up calls, clinicians review the following: 1) home practice, 2) problems or difficulties with home practice, 3) how the dyad worked together, 4) how the client felt completing home practice, 5) any changes to home practice that seem necessary, and 6) any patterns (common symptoms, reactions, helpful coping tools) that may have emerged since the last session.

Spaced Retrieval

SR is an evidence-based method for improving encoding and retrieval (Camp, 2006). As SR relies primarily on procedural memory, which remains intact late into the progression of dementia, motor activity is incorporated into the learning process whenever possible. The SR technique consists of repeated trials of retrieving target information at increasing intervals of time. When retrieval failure occurs (e.g., client forgets response), the clinician gives the client the correct information and asks him/her to repeat it immediately. The next retrieval interval is shortened to the most recent successful retrieval interval. The interval continues to decrease until the client provides the correct answer, at which time expansion of the retrieval interval occurs again, until there is an error. SR should be used when clients display difficulty remembering to use skills. The collateral may use SR to practice any skill,

and the clinician may use telephone booster calls with both the client and collateral to reinforce SR training.

The generalizability of SR may be increased if internal or external cues that can act as a stimulus and be linked to the coping behavior (response) are identified. Linking the coping behavior to external environmental cues (e.g., a ringing clock) or internal cues (e.g., heart racing) will help the client to establish a maintenance system. Concrete behavioral goals should be provided by clinicians, and these behaviors should be executed during the last SR training of the session if they cannot be performed repeatedly. For example, if the goal is for the client to go on a walk when the alarm clock goes off, the bridge from the external cue to the execution of behavior may be made by actually setting the alarm to go off at the end of the session and having the client go on a walk.

PEACEFUL MIND INTRODUCTORY SESSION

Procedures

- 1. Explain the basic information about how the program works.
- **2.** Provide and review session outlines (Figure 1).
- 3. Provide and review workbooks.
- **4.** Review each person's roles.
- **5.** Review the importance of practice.

Purpose

The introductory session material is typically followed by the Awareness Module during the same first visit. The clinician begins the session by explaining the format and purpose of the treatment sessions by stating the following: Over the next few weeks¹, we are going to work on tools to help you cope with your anxiety². It takes practice to learn and remember new coping tools. We will try a few different coping tools and determine which are most helpful to you. I will also teach you and *your collateral* ways to help you remember how and when to use these coping tools. I will meet with you and *the collateral* once a week for up to an hour each time for the next 12 weeks. I will also be calling both of you once a week to see if the coping tool we practiced has been helpful and to answer any questions. During the week, both of you may also call me if you have questions or difficulties using the coping tools.

Additionally, the importance of practice is discussed. At the end of each session, we will develop some practice exercises for you to do during the next week. These exercises will help you remember the coping tools and give you an opportunity to practice them to decrease your anxiety. It is important that you practice these skills daily so that they can have a significant impact on your life. *Name of collateral* will help you with the practice exercises. Complete your forms at the same time every day. Try not to get frustrated if you forget to do the exercises. Just do them when you remember; or if it's already the next day, go on to the exercise for the next day. Home practice is important; we want you to try your best to complete the exercises. But, we also do not want the practice to become another source of *anxiety*.

Explain the use of workbooks. These workbooks will hold all the handouts, practice forms, and summaries from our sessions. You might want to think of this as a toolbox that holds all

¹Italics indicate a possible script the clinician may say.

²Underlined words indicate that the current word is to be replaced with a word personalized for the client.

your tools in one place. Please think of a good place to keep your toolbox that will help you remember to use it every day. Plan to bring your toolbox to every meeting.

Materials

- 1. Session outlines (Figure 1) for the clinician, the collateral, and the patient.
- 2. Workbooks for the client and collateral, including your name and the time and day of the week of telephone and in-person meetings on the first pages, a brief introduction to the treatment, and the first module pages.

Client and Collateral Roles

The roles of each person are explained. When we meet each week, my role is to teach you coping tools to decrease anxiety and help you learn how to use them. Your job (gesture toward client) is to practice them every day, and let me know how they are working. And your job (gesture towards collateral) is to support *the client* in using his/her new tools in ways that we will decide each week. I will give you a form that provides a plan to help you practice using the coping tool you will be working with this week (Figure 2).

MODULE A: AWARENESS

Procedures

- 1. Discuss client and collateral handouts explaining awareness (Figure 3) and prepared awareness forms (Figure 4).
- **2.** Decide how the dyad will complete the awareness forms.
- **3.** Practice completing an awareness form, including how it will be completed between sessions.
- **4.** Provide awareness forms for each day.

Overview

Awareness promotes client and collateral knowledge of situations, antecedents, components, and consequences of anxiety. Daily monitoring gives the dyad an opportunity to record anxiety experiences at the time they occur. This can facilitate a discussion with the clinician and collateral about common triggers or reactions (thoughts, behaviors, physical signs, emotions, etc.), treatment goals, and monitoring of progress during the intervention.

Materials

- 1. Session outline, including a copy for the clinician, the collateral, and the client (Figure 1)
- **2.** Explanation of the purpose and how to complete awareness tool (Figure 3)
- 3. Form to record how and when the client and collateral will work together to complete awareness practice (Figure 2). This form will be filled in by the clinician during the session after helping the collateral and client decide when and how they will complete practice exercises (awareness).
- **4.** Prepared Awareness Tool Daily Practice forms dated for each day before the next week's session (Figure 4). Include extra forms for the collateral and client to practice completing during the session.

Awareness

Awareness forms can be modified with varying levels of complexity. Creating monitoring forms that are prefilled with anxiety-provoking situations and signs discussed during the pretreatment evaluation can simplify the self-monitoring process for clients with dementia, but these forms may be altered based on client and collateral input throughout treatment. Awareness forms require simply putting an X next to pre-identified situations and symptoms. Forms should use the client's terms for his/her anxiety triggers and reactions. Awareness forms are modified to focus on different symptoms and treatment goals as coping tools are added to the client's repertoire (e.g., less recording of symptoms and more recording of use of skills). Awareness may or may not be used during the entire course of treatment, depending on its helpfulness to the client.

Client and Collateral Roles

As with all skills taught, the way in which the client and collateral work together to complete awareness forms may vary depending on the dynamics of the client-collateral relationship as well as the cognitive abilities of the client. For example, the collateral may read items to the client, and the client or the collateral can mark the page, based on what the client says. Other clients may need only a daily reminder that it is time to fill out the monitoring form. Maximal client independence is optimal. Working together on awareness in session allows the clinician to observe the client and collateral interacting. The collateral's involvement in completing the forms may decrease as the client becomes more comfortable completing them.

MODULE B: BREATHING CHANGES

Procedures

- 1. Provide rationale for deep breathing.
- 2. Distribute and review instructional handouts for the client and collateral (Figure 5) for the breathing skill that the clinician feels is most appropriate.
- 3. Practice deep breathing.

Overview

Deep breathing is a relatively easy to teach, portable coping mechanism that can be effective in reducing anxiety. Often, when people are anxious or uneasy, breathing becomes rapid and shallow. By paying attention to your breathing and taking slow, deep breaths, you can actually make your entire body more relaxed. Breathing slowly and deeply from the diaphragm is a simple tool that you can use anywhere.

Materials

- **1.** Session outline, including a copy for the clinician, the collateral and the patient (Figure 1)
- 2. Appropriate "Breathing Changes" instructional forms (Based on pre-assessments, the clinician should determine which level of breathing skills is appropriate for the client and collateral: Basic, Advanced, or Respiratory Difficulties [Figure 5; Carter, Nicotra & Tucker, 1999]. The basic version of breathing retraining is appropriate for most clients, but the clinician may also offer more advanced training. Procedures designed for clients with respiratory difficulties can be used for any client.)

3. Form to record how and when the client and collateral will work together to complete breathing practice (Figure 2)

4. A week's worth of self-monitoring forms, including monitoring of deep breathing (see Figures 4 and 6 for the box that can be added to awareness forms to track deep breathing), labeled with day and date for the coming week and extra for practice and the collateral

Client and Collateral Roles

Collaterals learn and practice the skill with the client during the session. It may be helpful for clients and collaterals to practice guiding each other through the deep breathing insession and between sessions. For more cognitively impaired clients, collaterals likely will need to repeatedly demonstrate deep breathing to the client between sessions to help the client learn this skill. For less cognitively impaired clients, the skill may be quickly learned and the role of the collateral may just be to remind the client to practice deep breathing and to use the skill in stressful situations. Spaced retrieval may also be used to help clients learn to use this skill in stressful situations.

MODULE C: CALMING THOUGHTS

Procedures

- **1.** Introduce calming thoughts (Figure 7).
- 2. Choose calming thoughts.
- **3.** Decide how the collateral and client would like to work together to use calming thoughts.
- 4. Practice using calming thoughts.

Overview

Calming thoughts may be explained to the client and collateral in the following manner: What you think about before and during an anxious situation influences your emotions, how you behave, and how well you cope. A calming thought is a phrase you say to yourself that helps decrease your anxiety about a situation. It can be like an instruction to yourself or "self-talk." Some people's calming statements have been as follows: "Relax and take a deep breath"; "It's ok if I make a mistake"; "I can get through this"; or "I can do this." Let me tell you a story about how calming thoughts may be helpful: Paula noticed that her father was nervous when they were in the waiting room of his doctor's office. She reminded her father to say his coping statement, which was, "My daughter will help me through this."

After he said it, he seemed to feel more relaxed. Paula reminded him two more times while they were waiting to say, "My daughter will help me through this."

It is vital that the client believes in the validity of his/her calming thoughts for them to provide comfort. It may be necessary to spend significant time examining a new thought and breaking barriers in the client's or collateral's acceptance of this thought. Clients and collaterals may choose from the list of example calming thoughts (Figure 7) or develop their own.

Writing calming thoughts on an index card may help the client to remember them. These cards can be carried with the client in a pocket, wallet, or purse, placed on a bedside table or the refrigerator, or taped to a mirror. The client must be able to learn to remember to look at or notice a coping card placed in a commonly accessed or highly visible place for it to be

useful to them. Spaced retrieval may be useful to help the client learn to look at a coping card when anxious.

Materials

- **1.** Session outline (Figure 1)
- 2. Calming Thoughts instructional form, including examples of general calming thoughts (Figure 7; The clinician may add specific calming thoughts to use in situations that are distressing to particular clients. However, the clinician should be flexible during the session and consider input from the client and collateral about what calming thoughts might be most helpful.)
- **3.** Form to record how and when the client and collateral will work together to practice calming thoughts (Figure 2)
- **4.** A week's worth of self-monitoring forms, including monitoring calming thoughts (see Figures 4 and 8 for the box that can be added to awareness forms to track the use of several coping tools), labeled with day and date for the coming week and extra for practice and the collateral
- 5. Blank notecards and a marker

Client and Collateral Roles

This may be a difficult skill for more cognitively impaired clients to learn. For moderately cognitively impaired clients, calming statements should be very simple and concise. Collaterals should be taught to remind the client to look at his/her calming thoughts and practice them regularly, such as by prompting, "What can you say to yourself if you get anxious?" The initial use of calming thoughts may require extensive practice in-session and between sessions with the collateral. Collaterals should also be taught to remind the client to use the thoughts when they are with the client in an anxiety provoking situation. The ideal is to help the client learn to use the calming thoughts when anxious even when not reminded. However, if clients are unable to learn to use calming thoughts without prompting, this skill may still be useful. The collateral and the client have developed calming thoughts that help decrease anxiety as part of the treatment and the collateral may remind the client of these calming thoughts in stressful situations.

MODULE D: INCREASING ACTIVITY

Procedures

- 1. Provide rationale for increasing activities.
- 2. Assess current activities.
- **3.** Make an activity list (Figures 9 and 10).
- **4.** Decide on activities to increase (Figure 11).

Overview

Behavioral activation may help break patterns of inactivity and improve mood and satisfaction with life. The clinician uses concrete goals and daily practice assignments to encourage clients to participate in pleasurable activities. For the most benefit, collaterals should actively participate in these activities. Increasing activities may be explained to the clients and collaterals by saying: When people are feeling *anxious*, they often also feel sad or blue. Feeling *sad or anxious* may also decrease your energy and/or motivation to try activities, even activities that you once found enjoyable or rewarding. However,

participating in more rewarding activities may boost your mood and energy levels, and help you feel less *anxious* or *sad*. During this session, we will develop a plan to add more enjoyable activities to your daily life.

This module is initiated early enough in the treatment program to allow continued practice with increasing activities over a few weeks. If the behaviors trigger some anxiety, it is better to attempt them after the client has mastered at least one coping tool that may be used as an aid while attempting the new or increased behavior (e.g., deep breathing or calming thoughts).

It may take a few sessions to determine the most enjoyable and feasible way to incorporate more rewarding activities into the client's daily life. The discussion of increasing activities begins by discussing current activities and desires to increase or change them. The clinician inquires about patterns of avoidance or decreased involvement in pleasurable activities, as well as activities that clients currently enjoy or enjoyed in the past. Several handouts and worksheets may help in this process (Figures 9, 10, and 11).

Behaviors/activities selected should be accomplishable and likely to stimulate an increased sense of pleasure or achievement. Thus, the possible activities are highly flexible depending on client desires and abilities. Potential activities may be simplified modifications of the client's prior behavior. For instance, if a client enjoyed working in the garage, he could work in the garage again but with much simpler tasks, such as helping the collateral change the oil or dusting the inside of the car. Or, if he/she enjoyed cooking, they could help by peeling vegetables or mixing. The most important feature of the activity is that the client finds it enjoyable or gains a sense of achievement by participating in the activity. It is important to talk about possible obstacles in doing activities to assess feasibility and/or plan for contingencies to deal with likely obstacles should they occur. For example, if the client would like to go for a drive but his physician has recommended against driving, the group can brainstorm alternatives, such as going for a walk or a ride in the car. Activities may need to be separated into feasible steps. Breaking the activity into parts helps the client to gain a sense of achievement when smaller parts of a broader activity goal are achieved. Planning activities in a structured manner such as this may also help identify potential barriers to carrying out the activity and create plans for overcoming these barriers.

As more activities are added to the client's schedule, a calendar and/or a daily schedule may be helpful for planning and carrying out activities. However, some clients may prefer to have a list of activities written for them for each day, as a monthly or weekly calendar may contain too much information.

Materials

- **1.** Session outline (Figure 1)
- 2. List of Pleasant Activities (Figure 9; The clinician may present this list of activities designed for individuals with dementia. If clients are higher functioning, activity lists found in the behavior therapy literature may be used [e.g., Lejuez, Hopko, & Hopko, 2001].)
- **3.** Activities Ranking Form (Figure 10; This form helps the clinician, client, and collateral determine which activity to practice first.)
- **4.** Planning for an Activity worksheet (Figure 11; This worksheet helps the client and collateral break activities into smaller steps and identify what kind of help is necessary to carry out the activity.)

5. Form to record how and when the client and collateral will work together to increase pleasant activities (Figure 2)

6. Prepared Awareness Tool Daily Practice forms dated for each day before the next week's session (Figures 4 and 12) and extra forms for the collateral and for practice completing during the session (Behavioral activation may be incorporated into daily awareness [see Figure 12 for an example of an awareness form that includes several coping tools, including behavioral activation] and notecards or other forms of reminders of the client's coping tools [Figure 13].)

Client and Collateral Roles

Most clients will have difficulty initiating and/or completing new activities without the collateral's help. The amount of help needed will vary significantly with the level of cognitive and physical impairments. Collaterals may need to be actively involved in motivating the client, initiating the activity, supporting the client through the activity or even doing the activity alongside the client. More cognitively and physically impaired clients will require more active collateral involvement in the activity. For example, placing birdseed on the table may be enough encouragement for mildly impaired clients to carry through with the predetermined activity of feeding the birds, but for more impaired clients, the collateral may have to be with the client during the entire bird-feeding activity. Continued practice of the activity may help incorporate it into the client's routine and foster more independent behavior.

The clinician should encourage the collateral to present activities in a manner that fosters a sense of accomplishment (The garage needs to be cleaned. It would really help if you would sort these nuts and bolts into these jars.) and to refrain from communication that refers to the client's lack of abilities. Also, if the selected activity produces anxiety, the collateral may need to remind the client to use anxiety coping tools; or the client may need a new activity. Also, encourage the collateral to reinforce the client after difficult steps in any activity (praising the attempt or end product, placing the craft in a noticeable area, etc.). Highlighting differences in the client's mood after these activities also may increase future activities.

MODULE E: SLEEP SKILLS

Procedures

- 1. Explain the purpose of sleep skills.
- 2. Provide relevant sleep skills (a portion of Figure 14).
- **3.** Determine how sleep skills will be implemented.

Overview

Simple sleep-hygiene skills may be useful for clients with sleep difficulties that sometimes occur with anxiety. The following may be a good way to introduce this section: People experience more tiredness and have difficulty coping with anxiety or sadness when sleep is disrupted. This can lead to even more <u>anxiety or sadness</u>. Additionally, sleep is often disrupted when you are <u>anxious, stressed, worried, or sad</u>. In order to not overwhelm the client, especially more cognitive impaired clients, only sleep skills that have been determined to be more beneficial for the specific client being seen should be presented and of those, the client and collateral should choose only one or two at a time to implement.

Some sleep issues, such as sleep apnea, cannot be addressed by sleep skills; and the client should be referred to a physician if such problems are suspected.

Materials

- 1. Session Outline (Figure 1)
- 2. Sleep Skills handout (Figure 14; The clinician should ask enough questions to get a thorough assessment of which sleep skills would be most helpful and to modify handouts accordingly in a session before presenting sleep skills. See Stepanski, Rybarczyk, Lopez, & Stevens, 2003 for a guide for what questions to ask. Additional skills may be added as deemed beneficial.)
- **3.** Prepared Awareness Tool Daily Practice forms
- 4. Plan for how and when the client and collateral will work together to improve sleep

Client and Collateral Roles

These skills may be most useful for clients and collaterals who live together, as collaterals can encourage their use daily and nightly. Collaterals may need to incorporate skill use into their own routine if they share a bedroom with the client (e.g., going to bed at the same time nightly). If the collateral does not live with the client, however, he/she may still remind the client of these skills. It may be helpful for the collateral to place a notecard with the sleep skills next to the veteran's bed. Spaced retrieval may also help clients learn to use the skills such that they are asked, "What do you do before bed?" and then learn to recite and if possible perform the decided upon sleep skills. For more cognitively impaired clients, the collateral may need to instruct and even perform sleep activities daily and/or nightly with the client until they become a routine.

TERMINATION/TRANSITION SESSION

Procedures

- 1. Reinforce the client's and collateral's efforts during treatment.
- **2.** Review the tools covered during treatment (Figure 15).
- 3. Discuss which tools the dyad found particularly helpful (Figure 16).
- **4.** Encourage continued use of the tools (Figure 17).
- **5.** Discuss future telephone meetings.

Overview

This session is used to summarize all skills and treatment progress and to encourage skill maintenance after termination. One of the most important ways to do this is to identify particular difficulties the client and collateral were having prior to treatment, how they improved, and what skills helped to improve functioning. Handouts review the skills and delineate which skills the client will continue using. This is the last in-person session. After this session, the client will be followed through telephone calls once a week for 4 weeks, then every other week for 8 weeks.

Materials

- 1. Session outlines
- **2.** List of Tools (Figure 15; Prior to beginning the session, the clinician should prepare a summary sheet of the skills the client has learned.)
- **3.** Tools Summary (Figure 16; During the session, the client and collateral will use this form to list the skills they found particularly helpful and if/how these tools will be used after termination.)

4. Relapse Prevention (Figure 17; This form may be used to plan what to do if a relapse occurs.)

Client and Collateral Roles

The collateral should be encouraged to take over some of the responsibilities of the clinician, such as designing new activities and new calming thoughts, as well as encouraging the client to practice the skills learned during treatment. The collateral may even think of new coping tools that were not taught during treatment. The minimum level of collateral involvement that is needed for clients to engage in the skills while still encouraging independence will most likely be clear by the termination session and the clinician should encourage this continued level of involvement The client and the collateral should be reminded that more increased involvement may be necessary if new tools are added to their repertoire. Encourage both the collateral and the client to refer back to their workbooks as a resource to remind them of the tools learned during treatment. Remind the client and collateral that episodes of anxiety may occur again in the future, but that the tools they have learned can help reduce the anxiety sooner. It may be helpful to address concerns regarding how to cope with further declines in cognitive functioning following termination. The dyad should be told that the skills learned will likely continue to be helpful, but with increased collateral involvement, which may involve more reminders or more participating in tool use alongside the client.

BOOSTER TELEPHONE SESSIONS

Booster sessions are used to monitor the client's and collateral's progress with the skills and provide clinical assistance when necessary. For the first month after treatment, the booster calls with the client and collateral occur once a week. For the second and third month after treatment, booster calls with client and collateral occur once every other week. Booster calls should include the following elements:

- 1. How life is going in general
- Status of anxiety/nervousness symptoms or other emotional difficulties (e.g., depression, sleep problems)
- 3. Use of tools from the program and if so, which ones, and how
- 4. Questions regarding use of tools
- **5.** Review of tools as appropriate (use SR techniques if appropriate)
- 6. How the client and collateral have been working together

DISCUSSION

This manual provides the structure and content for a cognitive behavioral treatment of anxiety in persons with dementia. It is meant to be a flexible and adaptable manual due to the varying needs and abilities of the population. An open trial (Paukert et al., 2010) and a small, randomized clinical trial (Stanley et al., 2012) utilizing this manual indicate that people with dementia and their caregivers are able to participate in the treatment, are satisfied with the intervention, and benefit in terms of client anxiety and caregiver distress. However, these trials have also indicated that treatment effects decrease over time (from 3 month to 6 month follow-up), and it may be beneficial for treatment to be expanded over a longer length of time. Larger clinical trials with longer treatment and follow-up phases are necessary to investigate the efficacy of the treatment in this population.

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Date

We are meeting with <u>clinician's name</u> today to work on learning new tools for coping with <u>client's word for feeling.</u> Today's meeting will include:

- 1. Introduction to the treatment
- 2. Workbooks
- 3. Awareness
- 4. Practice

Next telephone appointment:

Next in-person appointment:

Figure 1. Sample Session Outline for the First Session

Goals for (insert week dates) this week are:
How I will work with <u>name of collateral or client</u> this week:
When I will practice this week:
Practice Tips
1. Choose a regular practice time once a day.
2. Place the workbook in the same visible place each day.
3. Don't get frustrated if you forget to practice - Just do it when you are
reminded or remember.

Figure 2. Plan for practicing coping tools

Awareness

The Awareness tool is the first coping tool we will put in your toolbox. Purpose

- Tracking symptoms helps you better understand your <u>anxiety</u>.
- It's hard to remember details of <u>anxiety</u> situations, including emotions, thoughts, behaviors, physical feelings, or fears over time.
- The awareness forms give you the opportunity to note your <u>anxiety</u> experience every day.
- When you understand your <u>anxiety</u> better, you'll be able to do a better job using other tools we'll learn in the next weeks to decrease it.
- Many people find that just understanding their <u>anxiety</u> improves their ability to cope with it.
- These forms include the situations and/or symptoms that you told us about that cause you to be concerned.
- Filling out these forms will help us monitor and plan your treatment to help ease your concerns.

Practice

- The awareness forms give you and <u>collateral</u> a chance to practice working together as a team.
- In the first box, put a mark next to the situations in which you were anxious today.
- In the second box, put a mark next to signs that you were anxious today.
- If there are other situations that made you feel anxious or indications that you were anxious, please indicate these in the blank space.
- It may take a few weeks to get used to these forms.

Figure 3. Awareness Handout

1. Things I Feel	Uneasy About
Getting a Headache	Asking for Help
Closed Door	Daughter
Having Enough Food	Being in a New Place
Other	
2. Other Signs That I'm Uneasy	
Calling Daughter for Help	Re-Opening Door
Checking Fridge	Waking up at Night
Other	Butterflies in my
	Stomach

Figure 4. Sample Awareness Form (Client's Term for *Anxiety* was *Uneasy*).

Basic Breathing Steps:

- 1) Take slow, even, deep breaths.
- 2) Inhale while counting slowly... 1, 2, 3.
- 3) Exhale while counting slowly... 1, 2, 3.
- 4) Practice this with your eyes closed.

Advanced Breathing Steps (After mastering the basic breathing steps, try this):

- 1) Put your hand on your stomach, with your little finger about 1 inch from your navel.
- 2) Focus on your breathing your hand should move out as you inhale and in as you exhale.
- 3) Breathe in a bit more slowly, evenly, and deeply; then breathe out slowly. As soon as you finish inhaling, begin to exhale.

Breathing for People with Respiratory Problems (Pursed Lip Breathing) Steps:

- 1) Inhale normally through your nose with your mouth closed.
- 2) Position your lips in a pursed or kissing position and exhale slowly through pursed lips.
- 3) Inhale slowly through your nose your abdomen should expand downward and outward.
- 4) Concentrate on breathing slowly and deeply twice as long for exhaling as for inhaling.
- 5) After several breaths, rest briefly. If you feel light-headed, go back to breathing normally and rest for a short time.

Figure 5.
Deep Breathing Skill (Carter, Nicotra & Tucker, 1999)

Did I use the breathing exercise today?	
Did I use breathing when I thought about an	
anxious situation today?YesNo	
Did I practice my breathing?YesNo	
Was breathing helpful today?YesNo	

Figure 6.Tracking Deep Breathing Practice Box for Awareness Forms

Calming thoughts

A calming thought is a statement or short sentence that you say to yourself that helps decrease your anxiety about a situation. It can be like an instruction to yourself or self-talk.

Examples:

Relax and take a deep breath.

It is okay if I make a mistake.

I'll take things one step at a time.

I can do this.

I can do what I need to do, even though I am anxious.

I can deal with this situation.

I know who to ask for help if I need it.

Worrying won't help anything.

Don't think about fear, just about what I have to do.

Even if I make mistakes, I will get through this.

This is not the worst thing in the world.

My anxiety won't hurt me.

I am doing everything I can to solve this problem.

Figure 7. Calming Thoughts Skill

3. Coping Tools Used Today:		
BreathingWhen down or uptightPractice	Calming thoughtsWhen down or uptightPractice	

Figure 8. Sample Box To Add to Awareness form To Track Multiple Tools

Pleasant Activity Ideas

* Buying something for yourself *Looking at a newspaper

* Listening to the radio *Reminiscing about old times

* Watching TV *Eating lunch with friends

* Getting a manicure *Watching people

* Finishing a task *Listening to music

* Laughing *Taking a walk

* Doing a puzzle *Reading magazines

*Visiting with neighbors *Eating a nice meal

Figure 9.

List of Pleasant Activities from Peaceful Living Manual (adapted from the treatment manual for the STAR-Caregivers treatment program; Teri, Huda, Gibbons, Young, & van Leynseele, 2005)

Activities That Would Be Fun	
	Rank

Figure 10. Activities Ranking Form

Choose an activity that is important to you at this time. It could be doing a task that helps you solve a problem or something that you would enjoy doing. List these below. Remember to pick something that you want to accomplish or that you enjoy or find satisfying. Choose something that is not too difficult and break it into small steps. Think about help you may need from others and be sure to include that in your steps.

The activity I am choosing is:

Step 1:	
Step 1: Step 2: Step 3:	
Step 3:	
Help I may need from someone else is:	

Figure 11. Planning for an Activity (From Calleo et al., in press).

1. Deen bre	athing use today
Did I practice deep breathing?	•
	YesNo
2. Calming Ti	hought use today
•	Yes No
Were calming thoughts helpful?	Yes No
	vities today
Did I do positive activities?	YesNo
Were positive activities helpful?	YesNo
	n response to which stressors?
Son's divorce	Stomach problems
Wife's medical problems	Not doing my projects
Other: Please list	

Figure 12.Sample Practice Form (Daily Awareness Form) for Multiple Coping Tools

When I feel uneasy, I can:

- Breathe deeply
- Do something fun:
 - o Go for a walk
 - Watch the history channel
 - o Build a model
 - O Put pictures in album
- Use my calming thought:
 - o I have help nearby if I need it.

Figure 13. Sample of Several Coping tools on a Notecard

* Most older adults sleep only 6 to 7 hours at night and then take a nap around lunchtime if they feel tired.

* Many people have trouble sleeping because they are worrying. If you do not get a good night's sleep, you can always get more the next night.

Nighttime Skills:

Go to sleep and wake up at the same time every day.

• Make sure the time between going to bed and getting up is about the same amount of time as you expect to sleep (typically, 7 to 8 hours).

Develop a routine or habit when it is time to get ready for bed. Stretch your legs or soak legs in a hot bath just before bed. Engage in a relaxing activity before bedtime or when waking up at night. Limit the use of the bed for sleep or intimacy with your partner. Get out of bed if you are not asleep in 15 to 20 minutes.

- If it is difficult for you to leave the bed at night, alter your bed or bedroom so that it is different during the time you are doing your calming or relaxing activity than it is when you try to sleep. For example, rather than leaving the bed for 15 to 20 minutes, turn the light on and/or prop yourself with pillows and read. When you are sleepy and ready to try to sleep, return to the original sleep situation (i.e., turn the light off, return pillows, put the book away).
- Remember, getting out of bed while groggy could be dangerous if you are prone to falling, so be careful!

Use other calming skills to help you sleep.

• If a thought is bothering you at night, write it down on a notepad you place next to your bed, or tell your loved one to remember it and put it out of your mind. This way, you and your loved one can think of a calming thought that addresses the bothersome thought in the morning. By leaving a bothering thought for the next day, you may also be able to figure out a solution to the problem at a later time. Trying to fall sleep is not the right environment for solving problems.

Make your bed and bedroom as conducive to sleep as possible.

- Minimize all distractions, such as light, noise, or movements that might be keeping you awake at night.
- You may consider such things as moving your bed or bedroom, putting curtains up, sleeping separately from your partner, sleeping with earplugs on, or anything else to minimize disturbances that keep you awake or awaken you.

Decrease pain.

- Relax the area of the body in which you feel pain.
- Distract yourself from pain by doing enjoyable things just before bed and by using calming thoughts when in bed.

Daytime Skills:

Do not nap or sleep after 3.

• If you are unable to avoid a nap mid-day, <u>limit the nap to 1 hour</u> and do not sleep after 3:00.

 Nap somewhere other than in your bed to decrease your nap time and help you to associate your bed with longer sleep times.

Do not drink caffeinated drinks in the afternoon.

• Caffeine can keep you awake for up to 8 hours, so do not drink caffeine 8 hours or less before normal bedtime.

Exercise at least 3 to 4 days per week <u>4 hours or more before normal</u> bedtime.

- Exercising in the morning or afternoon can help make you tired later in the day, but if you exercise too close to bedtime, it can raise your heart rate and body temperature and cause you to have more trouble falling asleep.
- Talk with your physician for exercise ideas that are safe and fit your needs.

Drink more fluids in the morning and less in the evening.

- You may be able to decrease getting up to go to the bathroom at night by decreasing the amount you drink in the evening. If your evening medications require fluids, then follow your medications' instructions.
- Be sure to drink more in the morning so that you get enough fluids to maintain your health.

Try spending a few minutes each morning in natural sunlight.

Figure 14. Sleep Skills

If helpful, use the numbered spaces below each tool to list how the client used the tools (e.g., calming statements used and activities that were increased).

<u>Awareness</u>

1.

2.

Deep Breathing

1.

2.

I remind myself to do deep breathing by:

Calming Thoughts

1.

2.

I remind myself of these calming thoughts by:

Activities

1.

2.

I remind myself to do these activities by:

Sleep Skills

1.

2.

I remind myself to do these activities by:

Figure 15. List of Tools

The following tools helped me:	
1	
2	
3	
4	
I will continue to use the tools daily by:	
1	
2	
3	
4	
<u>Collateral</u> will help me use the tools by:	
1	
2	
3	
4	

Figure 16. Tools Summary

What to do if I feel	_again:	
Indications that I feel	are:	
1		-
2		-
3		
4		
When I feel this way, I will:		
1		-
2		-
3		
4		
Collateral will help by:		
1		-
2		-
3		
4		

Figure 17. Relapse Prevention