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Cognitive-Behavioral Treatment for Anxiety in Patients With Dementia:

Two Case Studies

CYNTHIA A. KRAUS, PhD,

Michael E. DeBakey Veterans Affairs Medical Center, Houston, TX

PAUL SEIGNOUREL, PhD,

The University of Texas Medical School, Houston

VALLI BALASUBRAMANYAM, PhD,

Houston Center for Quality of Care & Utilization Studies

A. LYNN SNOW, PhD,

University of Alabama, Tuscaloosa Veterans Affairs Medical Center, and VA South Central Mental Illness Research, Education and Clinical Center

NANCY L. WILSON, MA, MSW,

Houston Center for Quality of Care & Utilization Studies, Michael E. DeBakey Veterans Affairs Medical Center, Houston, and Baylor College of Medicine

MARK E. KUNIK, MD, MPH,

Michael E. DeBakey Veterans Affairs Medical Center, Houston, VA South Central Mental Illness Research, Baylor College of Medicine, and Houston Center for Quality of Care & Utilization Studies

PAUL E. SCHULZ, MD, and

Michael E. DeBakey Veterans Affairs Medical Center and Baylor College of Medicine

MELINDA A. STANLEY, PhD

Menninger Department of Psychiatry and Behavioral Sciences, Michael E. DeBakey Veterans Affairs Medical Center, and VA South Central Mental Illness Research, and Houston Center for Quality of Care & Utilization Studies

Abstract

Anxiety is common in dementia and is associated with decreased independence and increased risk of nursing home placement. However, little is known about the treatment of anxiety in dementia. This article reports results from two patients who were treated with a modified version of cognitive-behavioral therapy for anxiety in dementia (CBT-AD). Modifications were made in the content, structure, and learning strategies of CBT to adapt skills to the cognitive limitations of these patients and include collaterals (i.e., family members, friends, or other caregivers) in the treatment process. The patients received education and awareness training and were taught the skills of diaphragmatic breathing, coping self-statements, exposure, and behavioral activation. The Clinical Dementia Rating (CDR) Scale was used to characterize dementia severity and determine eligibility for treatment (a CDR score of 0.5 to 2.0 was required for participation). Other measures included the Rating Anxiety in Dementia scale, the Neuropsychiatric Inventory Anxiety subscale, and the Mini International Neuropsychiatric Interview. Outcome data showed improvement in anxiety as measured by

standardized rating scales. We conclude that CBT-AD is potentially useful in treating anxiety in dementia patients and that this technique merits further study.

Keywords

dementia; anxiety; cognitive-behavioral therapy; caregivers; collaterals

Anxiety is a common coexisting complaint in patients with dementia,¹ and it can have a significant negative impact on the patient and his or her caregivers (collateral individuals). In individuals with dementia, the prevalence of anxiety ranges from 5% to 21% for anxiety disorders, and from 8% to 71% for anxiety symptoms.² When anxiety co-occurs with dementia, it has been associated with additional burden on patients and caregivers, since it can contribute to decreased independence,^{3,4} increased limitations on activities of daily living, increased behavioral problems,⁵ and a greater risk for nursing home placement.⁶ Despite its significant impact, no controlled clinical trials have addressed the treatment of anxiety in patients with dementia. Treatment of anxiety in these patients is complicated by their increased vulnerability to the cognitive side effects of medications commonly used to treat anxiety. For example, benzodiazepines, which are frequently used for anxiety in cognitively intact older adults,⁷ can have an additional impact on attention, memory, and motor function in patients with dementia.⁸ A psychosocial intervention may be preferable because of the increased vulnerability to adverse drug reactions, preexisting medical conditions, and complicated medication regimens often present in this population. Moreover, older adults generally report a preference for interventions other than medication.⁹⁻¹¹

Here we describe a new approach, derived from cognitive-behavioral interventions with demonstrated efficacy in cognitively intact older adults¹²⁻¹⁴ for treating anxiety in dementia. The potential usefulness of this treatment is illustrated in two patients with dementia and clinically significant anxiety.

Cognitive Behavioral Therapy

Cognitive-behavioral therapy (CBT) is the psychosocial intervention of choice for anxiety in younger adults.¹⁵ It has also been shown to reduce anxiety in cognitively intact older adults with generalized anxiety disorder.^{12,13,16} In addition, cognitive-behavioral interventions have been used effectively for many problems (including depression, reduced social skills, acute stress disorder, and problem behaviors) in other cognitively impaired populations (e.g., persons with mental retardation, traumatic brain injury, multiple sclerosis, and executive dysfunction).¹⁷⁻²⁰ Furthermore, case reports have shown positive results of CBT for anxiety and depression in persons with dementia.^{21,22}

Collaterals (caregivers) may play an important role in the implementation and success of CBT in this population. For instance, behavioral treatments implemented by caregivers have been used successfully to treat depression^{23,24} and agitation²⁵ in persons with dementia. Behavior management applied by nursing home staff has also shown some success.^{26,27}

CBT for Anxiety in Dementia (CBT-AD)

Based on these findings, our current and prior approaches for reducing anxiety and depression in later life^{13,14} were modified to meet the needs of patients with coexisting anxiety and dementia, an approach we termed CBT-AD. One difficulty in implementing CBT in individuals with dementia is that cognitive limitations may affect patients' ability to comprehend, learn, remember, and apply the skills learned in therapy. Thus, adjustments are needed in the content, structure, and learning strategies involved in treatment. In CBT-AD, we simplified skills such

as education and awareness training, diaphragmatic breathing, coping self-statements, exposure, and behavioral activation. We further enhanced comprehension and encoding by having patients repeat information to ensure their understanding and actively participate in creating retrieval/reminder cues (e.g., reminder cards, calendars). Collaterals were involved in treatment as “coaches” to facilitate learning and memory, and telephone contact between sessions was used to answer questions and encourage ongoing practice.

We also employed spaced retrieval (SR), an evidence-based method for improving encoding and retrieval²⁸ that relies on procedural memory, which remains relatively intact late into dementia’s progression. SR is a memory intervention that lets individuals practice successfully recalling information over progressively longer intervals of time. Sessions are set up with the therapist asking a question such as, “What is your room number?” and the patient responding with the correct answer, “My room number is 216.” These question-and-answer dialogues are interspersed with normal conversation. The correct response is the targeted information to be remembered. If the patient gives the correct response, the strategy is to let progressively longer periods of time elapse before asking the question again. If the patient gives an incorrect response, one then provides the correct information and immediately gives the patient an opportunity for successful recall. The time interval is then shortened to the most recent interval at which the retrieval was successful and subsequently decreased until the correct information is recalled. At this point, time intervals are again expanded until the occurrence of an error.²⁹ SR has been beneficial for individuals with dementia in many interventions, such as learning to engage in occupational therapy tasks or remember the route to their room.^{28,30-33} It has also been effectively implemented by caregivers of persons with dementia.^{34,35}

To accommodate for limited attention and fatigue in persons with dementia, sessions were generally shortened to 30 to 40 minutes and limited to one or two skills. The collateral, or caregiver, was present during each session so that he or she could become familiar with the skills to be learned and serve as a coach to help the patient practice skills between sessions. There was no required amount of collateral involvement outside the sessions. The coaching role was determined uniquely for each patient and caregiver dyad by the patient’s needs, preferences, and cognitive abilities, as well as the availability of the collateral. During each session, simplified written instructions and a concrete plan for homework completion were provided (e.g., designating regular times for patients to complete exercises and designating how and when their collaterals were going to be involved in the practice of the anxiety-reducing skill).

Study Design

The CBT-AD protocol was developed, piloted, and modified over 2 years in a series of seven participants. The two participants described in this report are representative of the individuals we intend to treat with this protocol. Participants were recruited from the Michael E. DeBakey Veterans Affairs Medical Center (MED-VAMC). This study was approved by the Baylor College of Medicine Institutional Review Board and the MED-VAMC Research and Development Committee.

Measures

Several measures were used to determine patients’ eligibility and to evaluate outcomes. The Clinical Dementia Rating Scale (CDR)³⁶ was used to characterize severity of dementia and determine eligibility for treatment (participants were required to have a CDR score of 0.5-2.0). CDR scores range from 0 (no impairment) to 3 (severe dementia). The Rating Anxiety in Dementia scale (RAID)³⁷ was used as the primary outcome measure of anxiety symptoms. This 20-item measure was administered as an interview with the patient and collateral, with a score of 11 or higher indicating clinically significant anxiety.³⁷ The Neuropsychiatric

Inventory (NPI)-Anxiety subscale³⁸ was used as a secondary measure of anxiety symptoms; it is administered to the collateral only. It includes seven items and provides scores for the frequency and severity of the patient's anxiety symptoms, as well as collateral (caregiver) distress. Patients and collaterals were also administered the Mini-International Neuropsychiatric Interview (MINI)³⁹ to determine the patient's psychiatric diagnoses.

CASE REPORTS

Patient 1

Mr. A is a 72-year-old, married Caucasian male veteran who was referred from the neurology clinic of a Veterans Affairs (VA) hospital. He finished 8th grade and completed his GED certification while in the service. He was diagnosed with possible Alzheimer's disease and had a history of hypertension, hyperlipidemia, and diabetes mellitus. Mr. A used braces as a result of a fall that occurred a few years earlier. About 3 years before our initial evaluation, he began to have tremors in both upper and lower extremities.

Mr. A and his wife reported that he had experienced marked impairment in his ability to engage in activities of daily living over the past few years. Mr. A's wife also reported a gradual decline in her husband's cognitive functioning over the preceding 2 years, including poor memory, especially for conversations and instructions, and disorientation. Because of his cognitive impairment, Mr. A had stopped driving 1 year before this evaluation. He had also been showing increased agitation during this time. He reported that he had been an anxious person throughout his life, but that his anxiety had worsened over the last few years.

Mr. A's wife participated as his collateral and was present during the assessments and for each session. Mr. A did not meet criteria for any psychiatric diagnosis according to the MINI and had a CDR score of 1, indicating mild dementia. His baseline assessment indicated worries about physical health and trivial matters (e.g., doing household chores properly, going to the grocery), as well as physical symptoms, including hand tremors, headaches, lightheadedness, numbness in hands and feet, and feeling restless and jittery. His responses on the RAID (RAID = 19) indicated clinically significant symptoms of anxiety. Mr. A's wife perceived his anxiety as significant (NPI anxiety total score = 4) and reported experiencing moderate distress related to her husband's anxiety (NPI caregiver distress = 3).

Mr. A and his wife participated in nine sessions over 10 weeks at the VA hospital. Meetings occurred about once a week, with each session lasting 30-45 minutes. Brief phone calls with the patient occurred once a week between sessions to assess for and address difficulties using the skills learned during the previous session. The therapist helped the patient and collateral problemsolve around any difficulties using the skills.

The first few sessions focused on anxiety monitoring and deep breathing. Mr. A kept daily records of his anxiety by marking a checklist of anxiety-producing situations and physical signs of anxiety (e.g., trivial matters, physical pain and numbness from wearing his leg braces). Deep breathing was taught by asking Mr. A to pay close attention to his breathing and to begin to take slow, even, deep breaths. He was asked to practice this exercise and use it whenever he noticed any feelings or physical symptoms of anxiety. He practiced deep breathing daily, sometimes with his wife, and learned to use it effectively in stressful situations, such as when he was in heavy traffic or in extreme weather conditions.

Beginning with the fourth treatment session, the focus shifted to teaching Mr. A to use coping statements, short sentences that Mr. A could say to himself to reduce his anxiety. Coping statements, which were selected and adapted from a list of examples provided to Mr. A, were practiced during sessions. Statements that Mr. A chose included, "It's not the worst thing in

the world,” while waiting a long time for a doctor’s appointment, and, “Don’t worry about it; I’ll see them another time,” when handling disappointment when his family could not visit him during the holidays. Based on Mr. A’s self-report, coping statements reduced his anxiety and decreased his tremors.

During the seventh session, behavioral activation was introduced^{40,41} as a strategy for increasing pleasure and distracting Mr. A from an anxious mood. From a checklist of activities, Mr. A endorsed that he enjoyed walking in the neighborhood park, mall, and grocery store; listening to gospel music; and fishing. He and his wife also decided that they wanted to create a family photo album. These activities were assigned as homework, one activity per week; however, Mr. A was frequently able to engage in multiple activities per week. The remaining two sessions (8 and 9) were focused on reviewing skills and continuing to increase Mr. A’s activity level. During these 2 weeks, Mr. A continued to participate in pleasurable activities, which were structured as homework assignments. As he engaged in more activities, his physical discomfort with wearing the leg braces decreased. Participation in these activities became easier with physical aids, such as holding on to the shopping cart when in a grocery store, or using his walker when in his neighborhood mall and park. Mr. A felt positive about being encouraged to engage in these activities, which he stated he had neglected because of difficulty with his gait, discomfort from his leg braces, and tremors.

Mr. A’s post-treatment assessment indicated a decrease in his anxiety according to the RAID (pre RAID = 19, post RAID = 10). His wife also commented about how he had benefited from treatment, including decreased restlessness, improved mood, and increased participation in pleasurable activities. Caregiver distress, measured by the NPI, decreased only minimally at post-treatment assessment (pre- = 3, post- = 2), and NPI Anxiety remained the same (post-NPI Anxiety = 4).

During a subsequent 3-month period, Mr. A and his wife were called weekly for 1 month and then bi-weekly for 2 months to facilitate continued use of coping skills. At each phone call, the therapist assessed skill use and problem-solved around any difficulties reported. During this time, Mr. A was able to continue using his coping skills independently without much aid from his wife. Mr. A used deep breathing and behavioral activation on a regular basis. He continued to put pictures in photo albums and go on shopping trips and outings with his wife using a walker and holding onto the shopping cart. A 6-month follow-up assessment consisted of re-administering the RAID and NPI to patient and collateral. Results revealed a further decrease in anxiety based on a RAID score of 7. Caregiver distress, measured by the NPI, remained approximately at baseline levels (NPI Caregiver distress, 6-month follow-up = 3), and the NPI Anxiety score remained at a 4 at the post-treatment and 6-month follow-ups.

Patient 2

Mr. B was an 82-year-old, widowed Caucasian male with 12 years of education who was referred to our study by his neurologist for generalized anxiety symptoms. He had a history of chronic obstructive pulmonary disease (COPD), prostate cancer, and coronary artery disease. He did not have any history of a psychiatric diagnosis or treatment, although his children reported that he had always been an “anxious” person. A few months before this intervention, he was living independently when he experienced a series of medical problems, including a worsening of his COPD, that required hospitalization. After the hospitalization, his son and daughter noticed a dramatic decline in Mr. B’s cognitive function. He was seen by the neurology department and diagnosed with possible Alzheimer’s disease (AD), which may have been worsened by sleep apnea related to COPD. After his hospitalization, Mr. B was no longer able to live independently and moved to a rehabilitation/assisted-living facility.

Mr. B's son served as his primary collateral, and his daughter was also involved in several therapy sessions. Like Mr. A, Mr. B had a CDR score of 1. His diagnoses according to the MINI were generalized anxiety disorder and specific phobia (fear of falling). The initial assessment revealed that Mr. B worried frequently about financial problems and being left alone. He was also fearful of falling and stayed in his wheelchair, even though his physical condition would have allowed him to walk short distances. His physical symptoms included trembling, heart palpitations, poor sleep, and low energy. His baseline scores on the RAID and NPI suggested clinically significant anxiety (RAID = 12; NPI = 8). Mr. B's son reported minimal caregiver distress over Mr. B's anxiety difficulties (NPI Anxiety Caregiver Distress = 1).

Mr. B and his son participated in nine treatment sessions (each lasting 30-45 minutes) over 3 months at his rehabilitation/assisted-living facility, with brief phone calls between sessions to check on Mr. B's status and completion of homework. Initial therapy sessions were focused on monitoring anxiety and breathing, using procedures similar to those described for Mr. A above. Mr. B completed a checklist of anxiety symptoms daily with help from his son. Deep breathing was introduced with simplified procedures consisting of breathing deeply and slowly. Mr. B's son was trained to act as a coach, prompting his father to breathe slowly and reinforcing him for good effort. Mr. B practiced daily with his son and was encouraged to breathe deeply and slowly whenever he felt anxious. During the third session, SR was used to teach Mr. B to use deep breathing when he could not sleep at night. During SR, Mr. B was asked the question, "What can you do when you can't sleep at night?" and he practiced giving the verbal answer, "I can breathe slowly," followed by slow, deep breaths. This question and answer dialogue was interspersed with normal conversation throughout the session. These initial sessions resulted in reports of reduced anxiety and improved sleep and energy.

Next, Mr. B was encouraged to start walking, which he had described as provoking anxiety during the initial assessment. We had planned to teach him to use breathing to reduce his anxiety, but he did not report anxiety while walking and was able to practice daily alone or with his son. To further increase his activity level, Mr. B was encouraged to review the activity board of the facility with his son daily and to decide on one or two activities to attend. During the next few weeks, Mr. B started participating in organized activities at the facility, including bingo and card games; and he developed a circle of friends with whom he regularly played these games. His anxiety further decreased, and his sleep improved. Daily checklists of anxiety symptoms completed at that time by Mr. B and his son revealed minimal anxiety symptoms. During that period, Mr. B made several comments about how helpful treatment had been and how optimistic he was about increasing activities and getting better. His son also noted significant improvement and stated that, without the intervention, he wouldn't have known "what to do." The last session was spent reviewing progress and discussing plans for relapse prevention. Specifically, we reviewed signs that would suggest a worsening of Mr. B's anxiety, possible coping strategies (e.g., deep breathing), and referral information.

In addition to the specific interventions just described, another target of therapy was improving communication between Mr. B and his son. During the initial assessment, Mr. B's son stated that Mr. B did not "try hard enough," and he rarely encouraged or praised his father. The therapist used modeling to improve communication, frequently praising both Mr. B and his son for their participation, and emphasizing effort rather than perfect performance. After a few sessions, critical comments from Mr. B's son stopped, and he regularly praised his father for his progress.

Just before his post-treatment assessment, Mr. B fell from his bed and hurt his back. After this accident, he was unable to get out of bed for several days, and pain medications made him drowsy. He also became more frustrated and anxious. In conjunction with the post-treatment

assessment, the therapist delivered a brief intervention consisting of a review of breathing techniques and pleasant activities with Mr. B and his son. Scores at the post-treatment assessment revealed a decrease in RAID scores (pre = 12, post = 8) and NPI Anxiety scores (pre = 8, post = 1). Caregiver distress decreased a small amount (NPI Anxiety caregiver distress: pre = 1, post = 0). During the following 3-month maintenance period, telephone calls were conducted every 2 weeks with Mr. B's son. After an initial improvement when his back pain subsided, Mr. B experienced recurrent medical problems that contributed to decreased functioning and quality of life. He died from natural causes just a few days before the scheduled 6-month follow-up assessment.

DISCUSSION

Both patients described here had clinically meaningful reductions in anxiety after participating in modified CBT (CBT-AD). This suggests that CBT-AD may be valuable for reducing anxiety in individuals with mild dementia. Deep breathing and increasing activity may be especially useful. In addition, Mr. A reported benefiting from simple coping statements. Collateral individuals were included in the treatment of both patients to help the patients learn and practice skills between meetings. Incorporating collaterals may be critical to this intervention, as patients may not be able to rehearse, remember, and apply the skills taught in therapy without help. Collaterals were trained during sessions to serve as coaches for their loved ones, but they may have also benefited from practicing these skills in dealing with their own frustration and anxiety. Unfortunately, we did not measure caregiver anxiety.

These cases suggest ways in which CBT can be adapted to accommodate the limitations in comprehension, learning, attention, and initiative that are common in individuals with dementia. For example, tailoring simplified checklists so that they mainly require recognition skills can be helpful for self-monitoring and/or practice exercises. It is also important to encourage structure when working to accomplish CBT goals. For example, keeping a notebook with monitoring forms in the same place at the patient's residence facilitated documentation of homework practice exercises. Encouraging a regular practice time also helped CBT-AD activities to become part of the patients' and collaterals' routine. Other modifications included conducting sessions at a slower pace and structuring meetings to cover only one skill at a time. To help reduce frustration and discouragement, patients and collaterals were informed that it might take more than 1 week to master each skill. It was also useful to modify terms used in each session to match the patient's educational background and language preferences; for example, we used the term *uneasy* instead of *anxious* when applicable.

In addition to the specific skills taught during the intervention, nonspecific treatment components, such as giving a sense of hope and improving communication between patient and caregiver, may play an important role. Meetings and practice exercises facilitated patients and collaterals spending time together working on a project or goal. Future work with this intervention may include further collateral guidance on coaching and communicating with their loved one, as well as dealing with caregiver stress.

Within patients, the degree of change in scores on the RAID and NPI differed. This may be related to differences between these anxiety measures. The anxiety subscale item on the NPI is per collateral report only. The RAID addresses a broader range of anxiety symptoms and utilizes input from patients and collaterals, as well as any relevant information available (e.g., from referring providers). Hence, different patterns of change may emerge on these two measures.

Since our work with these patients, we have improved assessment procedures for future investigations of CBT-AD. For example, modifications have been made to the RAID to make

the administration more consistent across raters (i.e., more specific rating instructions). Caregiver distress is now measured more broadly. The single NPI item used here to assess caregiver distress may have been insufficiently sensitive to changes in distress. Current assessments include more structured evaluations of caregiver involvement on a weekly basis, patient and collateral feedback for each skill, skill use between sessions, and retention of skill use at post-treatment and follow-up phone calls and assessments. Collateral anxiety and depression will also be assessed by self-report measures.

Further developmental work is needed to improve CBT-AD treatment. This intervention also needs to be piloted with a broader range of participants with different levels of impairment. Despite the preliminary nature of our findings, results so far are promising and suggest that this approach warrants further evaluation in a randomized clinical trial.

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