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College of Osteopathic Medicine

Educating Caregivers to Help Improve Sleep in Persons with Dementia

PROGRAM MANUAL

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OBJECTIVE

The purpose of this sleep study manual is to describe the procedures and format for implementing a caregiver-focused intervention aimed at reducing sleep disturbances among persons with Alzheimer's disease (AD) and other dementing illnesses. The program includes a non-pharmacologic intervention delivered to caregivers in a group format with individual reinforcement, and aims to improve sleep through bright light exposure, exercise, and sleep hygiene practices. The program includes three brief (one hour) classes, one review class, and two phone calls. Group classes will be provided at Adult Day Care settings either before pick-up, after drop-off, or at another convenient time for the caregivers.

SESSION BY SESSION OUTLINE

WEEK-1-SESSION 1 (Education Session-1)

Overview of this week's session: *Today we will*

- *Introduce the group*
- *Talk about proposed intervention*
- *Discuss sleep norms/circadian rhythms/effect of aging and Alzheimer's disease on sleep*
- *Introduce the importance of goal setting*

INTRODUCTIONS: SCRIPT

> *We are doing this project because we recognize how difficult it can be for persons with dementia to get a good night's sleep. The purpose of this project is to try an intervention to help people with dementia sleep better at night. A similar program was done in Seattle, Washington, and it was found that by working with caregivers to try different ways to improve sleep for persons with dementia, both the person's sleep can be improved and the caregiver's stress can be reduced. While not everything we talk about in this study will work for you, we are hopeful that over the next few months we can learn together. I am the sleep educator for the study and you will be meeting me often for the next few weeks. I work with a team of professionals who are highly dedicated and involved with this project. We also have a group of students who will be around if any help is needed. Now let's introduce ourselves to each other so that we can know each other better.*
>
> ***Facilitate Group Discussion 1:*** Introductions of each group member

PROPOSED INTERVENTION: SCRIPT

Now, let's talk about some important components of today's class. We will teach you strategies to use with the PWD that have been demonstrated as effective in reducing sleep disturbances, and then together we will work with you to develop personal goals for using these strategies. After today, there will be two additional classes and two phone calls to reinforce these strategies.

OVERVIEW OF SLEEP EDUCATION: SCRIPT

First, we would like to find out what kind of sleep disturbances your PWD is experiencing. Have you noticed any patterns in the PWD's sleep? Do you think that the PWD does not have any sleep problems? We want to let you know that your experiences can vary across group members. Our discussions about sleep problems will also help each other by providing mutual support, comfort, and brainstorming some ideas for solving your PWD's particular unique sleep problem. In addition, if we share our personal difficulties in caring for our PWDs, it will build solidarity among us as group members and help each other along the way.

Facilitate Group Discussion 2: PWD's Sleep Disturbances

Now since we are aware of the different sleep problems that your PWD is experiencing, let's focus on some information on why people with dementia have sleep disturbances. We will first discuss the effects of aging and dementia on sleep. Next, we will focus on what are called the "homeostatic processes of sleep" and circadian rhythms (or "body clocks"). Finally, we will discuss what kind of sleep patterns are realistic expectations for persons with dementia.

EFFECTS OF AGING AND DEMENTIA ON SLEEP

The aging process itself can cause pronounced effects on our sleep. Sleep research has consistently demonstrated that aging is typically associated with an increase in nocturnal awakenings and a decrease in the amount of deep sleep we obtain. Because sleep becomes somewhat more 'shallow' and broken as we age, as we grow older we may notice a decrease in the quality of sleep we obtain. Although these changes set the stage for people developing problems falling and staying asleep, they do not guarantee such problems. However, because of these changes, it is probably unrealistic to expect that PWD will regain the type of sleep they enjoyed as an adolescent or young adult.

Illnesses that cause dementia, such as Alzheimer's disease, further disrupt sleep. There are additional changes to brain chemistry and neuronal structures that interfere with getting deep, uninterrupted sleep. Alzheimer's disease and other forms of dementia also affect the PWD's ability to think clearly and remember things. If they become confused when they wake up at night, they may become upset. If they are confused and upset, they may wander. This can make you worry about even sleeping at night, lest the PWD wake you up or do something unsafe while you are sleeping. If you don't sleep well, you also may not think as well or remember during the day, and your stress level can go up.

HOMEOSTATIC PROCESSES

Before attempting to change the PWD's sleep habits, it is important that you understand a bit about how sleep works. The term "homeostatic" refers to "sleep drive," that is, the fact that the longer you are awake, the sleepier you become. Such knowledge is important because many people with sleep disturbances adopt various counter-productive strategies to avoid sleep deprivation and to make up for lost sleep. For example, such practices as daytime napping, going to bed too early or 'sleeping in' following a poor night's sleep reduces the body's need to sleep at night. So even though these things are done in an effort to avoid or recover lost sleep, they can actually create a vicious cycle perpetuating the sleep problem. Therefore it is important that the PWD has a consistent bed/rising time and reduced daytime sleep.

CIRCADIAN RHYTHMS

"Circadian" refers to our internal body "clock" which affects many functions such as metabolism, body temperature, and sleep/wake behavior. From years of research, sleep experts now know that our circadian 'clocks' seem to work in roughly 24 hour cycles. For

example, if we monitor an individual's body temperature for several consecutive days, we will see a consistent up and down variation or rhythm in temperature across each 24 hour day. The temperature will tend to be at its lowest point around 3 or 4 AM, will rise through the morning and early afternoon, and will hit its peak around 3 or 4 PM. Subsequently, the temperature will begin to fall until it hits its low point approximately 24 hours after its last low point. Different physiological functions have their own circadian 'clock' and these clocks seem to have an influence on each other. For example, as body temperature rises, we tend to be more awake; as body temperature drops, we tend to become sleepier. Light is another factor that synchronizes our circadian sleep clock, which explains why we are typically awake when it is daytime and asleep when it is dark at night. Keeping a consistent bed and rising time and reducing daytime sleep periods can also help your circadian rhythms be stronger.

REALISTIC EXPECTATION ABOUT SLEEP PATTERNS IN DEMENTIA

One question you probably are asking yourself is, 'How much sleep does the PWD need each night?' Generally speaking, there is no commonly accepted nightly dosage of sleep recommended for adults of any age group. The reason we have no such recommendation to offer is that individuals vary greatly in their sleep needs. Although most normal adults obtain 6 to 8 hours of sleep per night, some individuals need as little as 3 or 4 hours of sleep to function effectively each day. In contrast, some individuals require 10 to 12 hours of sleep each night and are actually sleep deprived if they obtain only 8. The best way to know how much sleep the PWD needs is to think about how much sleep they preferred getting in their younger life, and to see if you can determine the amount of sleep that allows the PWD to function effectively during the day. As we talked about earlier, because of changes in the brain associated with both aging and their dementing illness, it may not be possible for the PWD to sleep as well as they did when they were younger. Nevertheless, we may be able to make his or her sleep better than it is currently.

GOALSETTING: (HANDOUT 2)

We have talked about some things that can increase a PWD's need for sleep and strengthen his/her circadian rhythms, such as reducing time napping during the day and having a consistent bed and rising time. Before setting up any goals for your PWD, however, we want you to know that these goals should be both realistic and targeted to your unique situation. For example, one of the most important things any of us can do to *improve our sleep is to have a standard wake up time every day. This helps our circadian "clock" work more efficiently. However, some PWD's may already have a standard wake up time but still are getting up multiple times in the night; it will be important over time to try to figure out what is causing these awakenings and see if we can reduce them. We also want everyone to know that goal setting will vary among the group members based on the PWD's individual sleep needs and preferred sleep routines.*

Facilitate group discussion 3: Goalsetting.

To understand goal setting better, let's work together as a group to identify one thing that you will try to change in your PWD's sleep scheduling or routine between now and the next group session. For example, if you were going to pick a consistent bed or rising time, when would it be? Would it be possible to reduce afternoon or evening napping to make it more likely he or she would need to sleep at night? If so, what would you change in the length or timing of his/her naps?

Now let's discuss the feasibility of each goal with the group. As we mentioned earlier our aim is to select a goal that is doable. You may be afraid that making these changes will be difficult or provoke new conflicts with the PWD. It may be that the PWD's napping, going to bed early, or sleeping in late is the only respite you get and you don't want to give it up. However, you won't know what will happen until you give it a try! Also, remember that many caregivers in previous studies have tried changing sleeping patterns for the PWD based on simple goals and it has proved worthwhile in the end. Are you willing to give it try, just for the next couple of weeks?

WEEK 2 -PHONE CALL 1

Phone call 1: This is our first phone call after the group sessions. I would first like to know how things are going with the sleep plan you developed in the last group? (After you get the caregiver in an active conversation the following subset of questions can be asked.) How are you doing keeping with the goal you set at our last group session? Have you noticed any changes (good or bad) in the PWD's sleep since then? Do you think your original goal was realistic, or should it be modified and if so, how? For example, maybe moving the PWD's bedtime back from 6 pm to 11 was unrealistic/too big a stretch and you can try 8 pm instead...

WEEK-3-SESSION 2 (Education Session-2)

Overview of this week's session: *Today we will*

- *Review the materials from last session*
- *Discuss the importance of physical activity and its impact on sleep.*
- *Discuss the importance of light and its impact on sleep*
- *Discuss sleep hygiene*
- *Goal setting*

REVIEW MATERIALS FROM LAST SESSION: SCRIPT

Let's discuss how the last week was for everyone? Did you feel that the information provided in the last class was useful? What are your thoughts on it…?

Facilitate group discussion 4: Current Exercise routine

Today we want to discuss your PWD's current exercise routine. What types of exercises does your PWD do on a daily basis? Do you face any challenges in following an existing exercise routine, or have any concerns about your PWD being able to exercise? After we are aware of each individual existing exercise plan (or no plan), we will discuss the importance of exercise on sleep. This will be helpful for us as well as the group.

EXERCISE AND IMPACT ON SLEEP: SCRIPT

We want all older adults, including PWDs, to exercise: it reduces boredom, increases muscle strength, reduces risk for falls, and is associated with better sleep and mood. The U.S. Surgeon General recommends that everyone should ideally exercise 30 minutes a day, and this is true for PWDs as well. However, it is not essential that these be 30 consecutive minutes, so people who are frail or unaccustomed to physical activity should start slow and build up, or break their exercise times into chunks throughout the day (e.g., 10 minutes, 3 times/day). You should talk with your doctor if you have any concerns about starting an increased activity program.

Suggestions for establishing a routine:

I. *The best way to set up an exercise or physical activity routine is to do something every day. If you skip one day, it is easy to skip the next one too. If you do it every day, it will become a habit.*
II. *The PWD may start with 5-10 minutes and gradually increase the time. Sometimes a routine for 30 minutes is easier to establish but if a person has been very inactive in the past, you don't want to do too much too soon and risk injury. This differs from person to person.*
III. *Exercising later in the day will reduce the tendency for napping during the daytime and increase sleep drive/need for sleep at night.*
IV. *Make it fun! Are there any exercise buddies in your family or circle of neighbors or friends who could walk with the PWD? It will be easier to stick with an exercise routine if you aren't the only person doing it with the PWD.*
V. *Mix it up! Walking is the easiest exercise for most people but you can do different kind of activities too, like water exercise, riding a stationary bike, or even ballroom dancing.*

Facilitate Group Discussion 5: Potential obstacles to establishing an exercise routine

As a group, discuss each of these possible challenges to exercise, and brainstorm solutions. For example:

Safety

I. *Proper footwear*
II. *Weather (heat, cold, icy, windy, electrical storms)*
III. *Safety and feasibility: Neighborhood condition-Hilly areas, walkability/sidewalks. Can you walk at a local big-box store or march in place in the hallway of your own home?*

IV. *PWD/caregiver have health/injury-related restrictions on their exercise activity*

Other Considerations

I. *PWD doesn't want to exercise*
II. *Caregiver doesn't like to exercise*

LIGHT AND IMPACT ON SLEEP: SCRIPT

We talked last session about how light is an important factor in setting our circadian clocks and so can impact sleep patterns. For example, having lots of light in the morning is going to make your body want to go to bed earlier at night; having more light late in the day tends to make your body want to go to bed later.

We have found in our research that exposure to bright light also can help PWD sleep more soundly. "Bright light" does not necessarily mean being out in the direct sun, but can include even just sitting near a window on a sunny day. It can also mean being outside even on cloudy days, because the kind of light that is good for your sleep reaches through the clouds. At this point, let's discuss some possible ways for your PWD to increase his or her daily exposure to light. We have to understand that these possibilities may differ across our group members. What may work for one may not work for others.

Some possibilities may be

- *Moving a favorite reading chair or breakfast table near the window.*
- *Making a ritual of going out on the porch or deck for tea at certain time of day.*
- *Walking during the day when the sun is out.*
- *Engaging in pleasant activities together outside like picking flowers.*
- *Opening curtains in the house.*
- *Some people find that having a bright light box turned on near the chair while they read, watch TV, or eat is an easy way to get additional light exposure. These light boxes are the kind used in indoor garden shops, and since they do not emit UV light that can cause sunburns they are very safe. Halogen lights should NOT be used because they can get hot and cause a fire risk.*

Research has shown than getting a minimum of 30-60 minutes of bright or natural outside light each day is ideal for helping sleep. It can also improve your mood. If you are able to spend time getting additional light exposure during the next few weeks, you should record this exposure in your log.

We also need to be aware of some safety issues while being exposed to bright light. Some of the common ones are:

- *Wearing sunscreen when you are outside*
- *Medications that increase sensitivity to light*
- *Drinking lots of fluids*
- *Some PWD do not like bright light and can get agitated*

In addition to increasing light during the day, it is important to reduce the amount of light the PWD is exposed to at night. Some PWD become very sensitive to any light *shining in from the street outside, from cars driving by, or even from the overhead smoke detector, and it will wake them up. Although PWDs need enough light in sleeping areas to be able to find their way to the bathroom and move about safely at night, it is better to use a small nightlight rather than to turn on overhead lights if s/he needs to get up.*

Facilitate group discussion 4: Exposure to Sunlight During the Day and Reducing Light at Night

SLEEP HYGIENE: SCRIPT (HANDOUT-3)

"Sleep hygiene" is a term that refers to setting up good sleep habits and an environment that is conducive to sleep (refer to handout 3). Recommended sleep hygiene strategies include avoiding non-sleep activities while in bed, such as watching TV, eating, reading, or using the phone. Let's review the Sleep Hygiene handout together and see if any of the recommendations might be things you would like to change.

Facilitate group discussion 6. Sleep hygiene

GOALSETTING (Handouts 1 & 2)

Review and establish goals to complete for the next class.

WEEK-4-SESSION 3 (Education Session-3)

Overview of this week's session: *today we will:*

- Review from last week : Obstacles/reinforcement of proposed treatments
- Modifying Goals/Problem Solving

REVIEW: OBSTACLES/REINFORCEMENT OF PROPOSED INTERVENTION: SCRIPT

We will primarily focus today on challenges that we encountered in the past weeks in terms of implementing and sticking to sleep scheduling/sleep hygiene, exercise, and light exposure goals that you've selected for the PWD. Let's discuss some of the challenges that you encountered in the past weeks. As a group we can then suggest some strategies for overcoming these challenges. We will also discuss as a group how we can modify our goals to achieve benefit.

Teaching Aid-Common obstacles to exercise

I. *Care-recipient doesn’t want to walk*
II. *Insufficient time*
III. *Competing responsibilities*
IV. *Age-related health conditions or physical concerns*
V. *Feeling like a failure when you don’t reach your goal*
VI. *Instability of goals (changing goals every week, not sticking with one goal to the end)*
VII. *Not feeling convinced that achieving a goal will really make a difference*
VIII. *Caregiver can’t/won’t walk and other exercise partner is not available*

Teaching Aid -Possible exercise-related problem-solving suggestions

I. *Specify or change time of day*
II. *Link goal behavior to established habit*
III. *Add or replace one activity with another*
IV. *Social support*
V. *Focus on goal achievement*
VI. *Use facility’s work gym*
VII. *Make exercise fun!*

Teaching Aid -Common obstacles to increasing light exposure

I. *Bright light is annoying*
II. *Light bothers your eyes or gives you a headache*
III. *Light makes you feel sleepy*
IV. *Light increases agitation*

Teaching Aid -Possible light exposure problem-solving suggestions

V. *Identify a range of activities for caregiver/care-recipient to use to pass the time*
VI. *Playing board games while sitting next to the window*
VII. *Discuss communication strategies for encouraging care-recipient to spend more time where it is light*

Teaching Aid -Common obstacles to caregiver motivation

Caregiving is associated with a range of physical, emotional, and social changes. These changes can make it difficult for caregivers to set sleep, exercise, or light exposure goals for the PWD. Ask caregiver what kind of changes s/he has experienced and how they may be impacting their participation in the goals for this class. Explore a variety of coping strategies that might be helpful for managing their unique situation, including (but not limited to):

I. *Respite: determine if there are community services or family and friends whom the caregiver could ask for assistance, including senior adult day programs for the person with dementia*
II. *Changing perspective: changing what one thinks or says about a situation can improve mood or ability to respond effectively*
III. *Education: knowing as much as possible about dementia and Alzheimer's disease*

GOALSETTING

Review and establish goals for the next class

WEEK-5-PHONE CALL 2

Phone call 2: Hi – I hope all is well with you. Is this a good time to talk? (If the caregiver says no, offer to reschedule.) The reason I called today was to see how things are going with the goals that you set for the PWD over the past few weeks. Have you been keeping to the sleep schedule goals you set? Have there been any changes in daytime napping routines? How is exercising and increasing daytime light/decreasing nighttime light working? Together we can try to figure out how to best help you achieve your goals or modify them as needed.

WEEK-6-TERMINATION SESSION (WRAP UP)

Overview of this week's session *today we will:*

- Feedback/Discuss what we learnt in previous weeks.

GROUPSHARING & FEEDBACK: SCRIPT

> *Your feedback from this intervention is really valuable. We will use this time to evaluate and obtain meaningful information about the program (Please use the feedback form in Appendix 1 to provide your suggestions). We will be providing the same intervention to many more groups and the challenges which you faced in the group will help other caregivers. As we all know, today is our last class and I want everyone to know that we are always available to provide any resources that we can. We may not be available to respond immediately but we will try to get back to you as soon as possible. Feedback on the program is one thing that we would like, but we also want to know how each one of you felt during these sessions. Were you too overwhelmed, relieved, stressed, bored… Lastly, in the remaining time, I want to use this platform for sharing our feelings, grief, and happiness….in caring for our loved ones.*

HANDOUT 1- GOAL WORKSHEET

GOAL WORKSHEET-WEEK (#   )

Goal # 1

…….

…….

Goal is important because………………………………………………………………………………………

……

Steps taken to reach this goal are……………………………………………………………………………

……

Goal # 2

…….

……

Goal is important because……………………………………………………………………………………….

……

Steps taken to reach this goal are…………………………………………………………………………….

……

HANDOUT 2-SLEEP HYGEINE

1. If you are having difficulty sleeping, get up and have some milk or a banana. They have the amino acid, tryptophan. Tryptophan is a safe and reasonably effective sleep aid, probably due to its ability to increase brain levels of serotonin (a calming neurotransmitter when present in moderate levels) and/or melatonin (a sleep-inducing hormone secreted by the pineal gland in response to darkness or low light levels).

2. Your sleeping room should be cool and dark. Block out light from blinds or windows with towels and close curtains.

3. Use a fan if necessary to ventilate the bedroom for more comfortable sleeping.

4. Do your exercising in the late afternoon. This will help prevent napping in the afternoon. It may have the added benefit of getting you in some outside light.

5. Do not rest a lot. Getting too much rest will not allow you to sleep well.

6. All disturbances such as TV, computers, phones, and pets interfere with sleep and should not be in the bedroom.

7. If you cannot sleep, take a warm bath and read something soothing, not anything that is exciting and stimulating for your brain. You need to be relaxed to sleep well. Practicing a relaxing meditation can help.

8. Avoid caffeine at bedtime, including coffee, tea, soda, and chocolate.

APPENDIX-1

FEEDBACK- SLEEP STUDY

The purpose of this evaluation form is to get appropriate feedback to maximize the impact of our sleep education program. Your participation is voluntary. The responses from this survey will be confidential. Thank You

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1. Name ------------------
2. What is your age? -------------------
3. What is your gender? -------------------
4. What is your education level?
   a. ● High School Graduate ● Partial High School
      ● College education ● Partial College Education
   b. ● Certification_______________________.
      ● Professional Degree (Master's Degree or higher)_____________________________.
5. Race

   ● Caucasian ● African American ● American Indian or Alaskan Native
   ● Native Hawaiian or other Pacific Islander ● Other
6. Ethnicity

   ● Hispanic or Latino ● Not Hispanic or Latino

For the next several questions please chose the appropriate box

7. Which of the following did you try to implement?

   ● Exercise ● Light ● Sleep hygiene
8. Did any of the interventions improve your loved one's sleep? If yes, please check which one:

   ● Exercise ● Light ● Sleep hygiene
9. How important was the goal-setting to the overall program?

   ● Very important ● Somewhat important ● Not important

10. Do you think that the duration of the program was appropriate for the material presented?

● Disagree ● Agree ● Neutral

11 Please tell us what, if anything, you learned from the program that you anticipate continuing with going forward?

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12. Do you think we should offer this program to other caregivers?

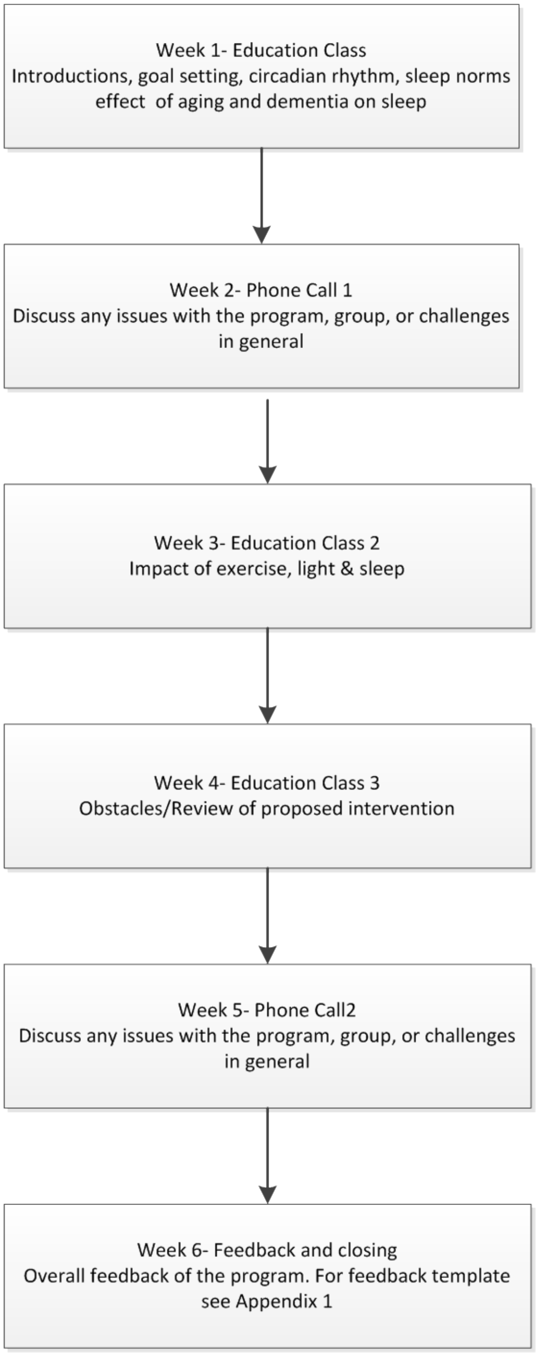
● Yes ● Maybe/Not sure ● No

13. How can the educational program be improved (please critique any aspect of the program you think is important including program material, program delivery, phone calls, etc.)?

THANK YOU

APPENDIX-2

PROGRAM FLOWCHART



Week 1- Education Class
Introductions, goal setting, circadian rhythm, sleep norms effect of aging and dementia on sleep

Week 2- Phone Call 1
Discuss any issues with the program, group, or challenges in general

Week 3- Education Class 2
Impact of exercise, light & sleep

Week 4- Education Class 3
Obstacles/Review of proposed intervention

Week 5- Phone Call2
Discuss any issues with the program, group, or challenges in general

Week 6- Feedback and closing
Overall feedback of the program. For feedback template see Appendix 1

APPENDIX-3

SUGGESTED READINGS

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4. McCurry, S.M., Gibbons, L.E., Logsdon, R.G., Vitiello, M.V., Teri, L. (2005). Nighttime Insomnia Treatment and Education for Alzheimer's Disease: a randomized, controlled trial. *Journal of American Geriatric Society, 53*:793–802.

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