Increase Caregiver's Participation In The Treatment Of Patients With Alzheimer's Disease.

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Background

Caring for someone with Dementia is a very challenging and emotionally draining task (1, 2). Older persons with long-term care needs—65%—rely exclusively on family and friends to provide assistance. Another 30% will supplement family care with assistance from paid providers. Studies show that an estimated 46-59% of caregivers are clinically depressed (3).

Objective

To demonstrate a working model of integrative treatment of patients with Dementia with an active caregiver's involvement.

Method and Results

Our program was based on work with more than several hundred caregivers and patients during the last ten years.

Presently, the goals of our integrative treatment are:

- To educate and to engage both (the patient and the caregiver) to be our active partners in successful treatment
- To prevent cognitive decline in patients for as long as possible
- To address caregiver's emotional state and to provide caregiver intensive support and help
- To work together with the patient and the caregiver as a team

An extensive assessment is conducted in the office or during home visits to reveal the patient's brain reserve and his capacity to do exercises.

During this time, the caregiver becomes an observer to see the preserved brain functions on one hand, and an active participant while learning the exercises, on the other hand.

Our model includes:

- Education of the patient and the caregiver
- Medications, vitamins and supplements recommendations
- Light, sounds and music stimulation
- Diet modification
- Cognitive (attention and memory) training (4)
- Homework assignments with specific recommendations for the length of exercises and number of repetitions.
- Mild physical exercises demonstration and training for the patient and the caregiver

At the first encounter we explain to the patient and caregiver, that today's treatment consists not only of simple medication administration, but also of using the body and brain natural healing power.

Non-pharmacological interventions are as important for successful treatment, as taking medications.

Continuous patient and caregivers education is an extremely important part of our program. At first, the patient and the caregivers are informed that the treatment of dementia at our Center is "very aggressive" because we believe that brain functions need to be activated as soon as possible. An active patient's involvement means that treatment "***starts at the office and continues at home***".

The same principals of brain activations are applicable for caregivers. They are under enormous ongoing stress, which causes decreased concentration, and memory, problems with planning and making decisions, anxiety and worries, overwhelming thoughts, and sleep disturbances. Doing joint exercises could also restore their own brain functions.

The education part of the program includes information about:

- Dementia, assessment of cognitive functions and brain reserves, option for the treatment
- Management of emergency situations
- Brain plasticity and possibility to utilize brain reserves
- Signs of feeling of burn-out and self-care options

The latest news about Dementia is always available in forms of our published articles, newsletter and handouts. Even though an education is an "extra" work for our office staff, there is always time to discuss the latest dementia news and to introduce new exercise or new recipe to the patient and caregiver.

Additionally, the caregiver's education include an information about the caregivers stress and health changes, their emotional reactions, starting from fear and anxiety and going on to apathy and depression and dynamic's changes in family relationships.

Intensive caregiver supports include:

- To provide the caregiver with the stress management tools (breathing exercises, relaxation training and meditation) and to encourage them to implement these techniques every day
- To teach the caregiver the simple, brief (one- two minutes) exercises (freeze-frame and others) to overcome acute frustration reactions (5)
- To teach the caregiver the coping skills to manage patient's behavior and emergency situations
- To teach the caregiver techniques to exercise for self-control

An increase caregiver's involvement is accomplished by:

- Observation of patient's reactions and behavior during testing procedures and computerized cognitive training exercises in the office
- Learning the intervention techniques by observing staff interactions with the patient, especially, when the patient gets irritable and frustrated
- Providing comprehensive report and feedback to the therapist about homework and its quality
- Participation in joint physical exercises at the office and at home and reporting to the therapist patient's reactions
- Providing report to the therapist about the caregiver's own emotional reactions and efficiency of self-help routine.
- Mastering caregiver skills to manage emergency situations with the patient
- Helping the patients to modify the diet and to increase water consumption

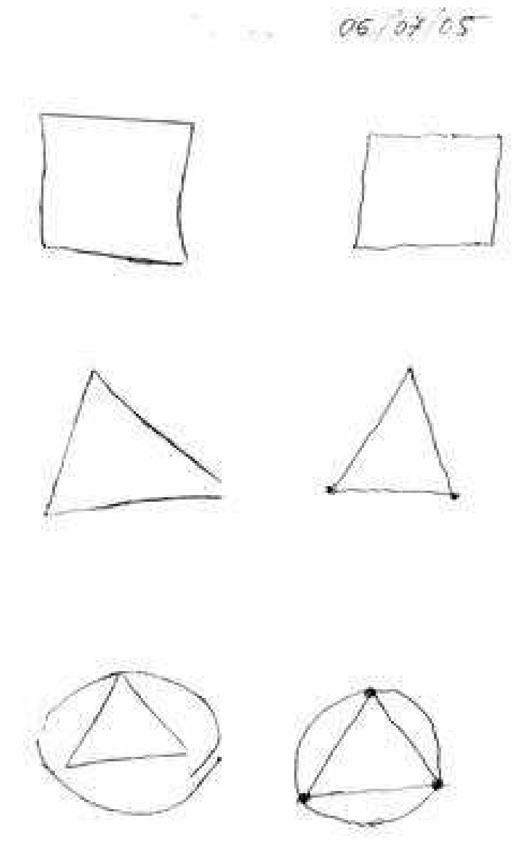

Figure 2

We encourage the caregiver to be an active participant, a helper and a supervisor. This approach will increase the efficiency of patient's work and to help the caregiver with his own emotional issues. Our exercises help the caregiver to regain concentration, attention and confidence as well. We encourage doing exercises together, regularly, 10-15 minutes, 2-3 times per day.

Many caregivers report feelings of reconnection with the patient, feelings of accomplishment. They have a more structured day, and feel that the time is spend more productively.

Working with fragile, elderly patients and their caregivers, we developed hands exercises, that have to be done only in sitting position. Some of exercises are accompanied by eye movements and sounds. They are very safe, easy to tolerate and to memorize.

The rational behind these exercises based on different bodily parts distribution in sensory-motor zone in the brain (figure 1). As you see from this picture, the hands, mouth and tongue occupied the most part of the sensory-motor strip in the cortex.

One possible explanation of this is the active usage of the hands, mouth and tongue by babies during the first 6 months of their life. The sensory stimulation and muscle movements of these body parts activate corresponding neurons and make them to expand their territory in the brain. Leg's active life begins later, when baby make attempts to stand up. This unequal body parts distribution remains in the brain for rest of our life.

Another theoretical point, related to the hand and legs activities and brain development, has to be mentioned.

It is well known, there are older and younger parts in the brain. For example, the frontal lobe is the youngest part of the brain as the result of human evolution. With aging this part of the brain becomes disabled first.

Figure 1

The cortical homunculus is a visual representation of the concept of "the body within the brain" that one's hand or face exists as much as a series of nerve structures or a "neuron concept" as it does a physical form

Leg's activities start later compare to the hands. When we get older, leg's activities go down first, but hands are still fully functioning. There is a lot of data, that confirms that the gait problems could be early signs of dementia (6,7).

Based on these assumptions, we developed the model of sensory-motor exercises, for brain activation: "Hands first – legs second". At the beginning of the treatment we introduce the hands exercises, and then gradually add the legs exercises. Later, while doing combined exercises the hands activities always preclude the legs movements.

As illustration of patient-caregiver collaboration in successful treatment, we present the case of one of our patients.

Patient U. is an 88-year old male, WWII veteran, retired engineer, who was brought in by his son and home aid for an evaluation of the possibility of treatment or nursing home placement.

According to the caregivers, the patient demonstrated decrease memory and concentration loss, inability to maintain the conversations, episodes of confusion, hallucinations, sadness, apathy, episodes of irritability and middle insomnia. Memory deterioration started insidiously about 5 years ago. He had hypertension, COPD, Asthma, an episode of acute renal failure due to urine retention, BPH.

On initial assessment (June 2005), he was oriented in person and place, was able to answer simple questions and follow simple commands, to perform the Lurie test and to write his name and copied simple and complex shapes (figure 2). MMSE was not possible to be done at that time.

Based on the interview and his preserved brain function (writing, constructions and abilities to repeat simple exercises), we asked the son to postpone the nursing home placement for several months and start active treatment.

He was given medications (Exelon, Zoloft, Namenda, B complex, Seroquel, Vitamin C, Fish oil, Vitamin E, and Folic Acid) and homework assignment to do simple hand exercises, writing letters, words, numbers, counting. They understood our approach and were determined to work with the patient regularly. Both patient and caregivers were enjoying joint exercises.

In 3 months (September 2005) the MMSE (figure 3, 4) and SIB were obtained for the first time His MMSE was 8 (see below) with a poor clock drawing and low verbal fluency test. SIB score was 88 out of 100.

For the duration of two years, the patient continued to do exercises, taking vitamins, and medications (except Zoloft and Seroquel). As result of this treatment, his depression was resolved, social interactions and attention improved. The caregiver noticed improved patient's behavior and communications. Patient cognition improved tremendously. His MMSE increased to 18 with a normal clock drawing and verbal fluency improvement (figure 5, 6). Even though the problems with short memory are still remained because of dementia, the attention, construction, long term memory and especially frontal lobe functions (clock drawing and verbal fluency) have improved.

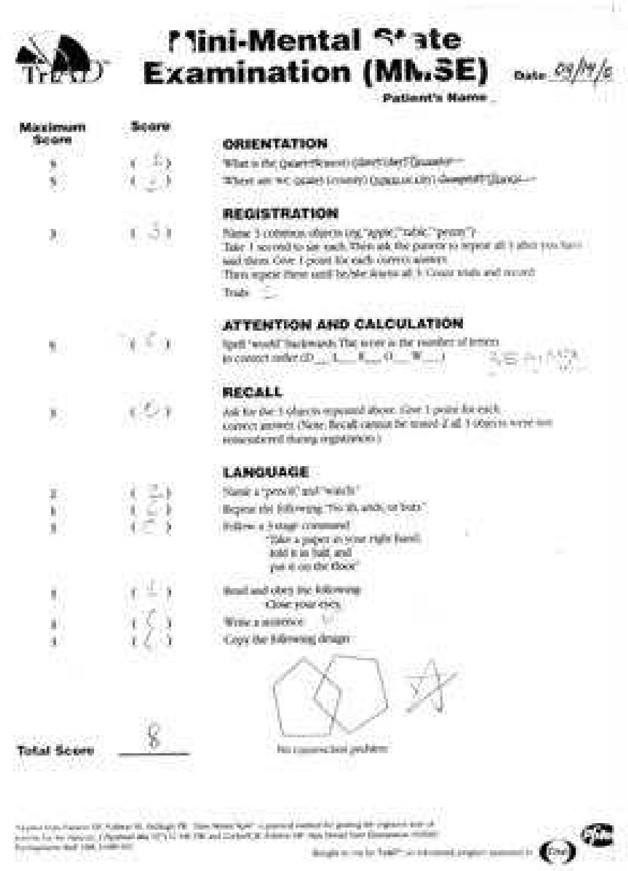

Figure 3

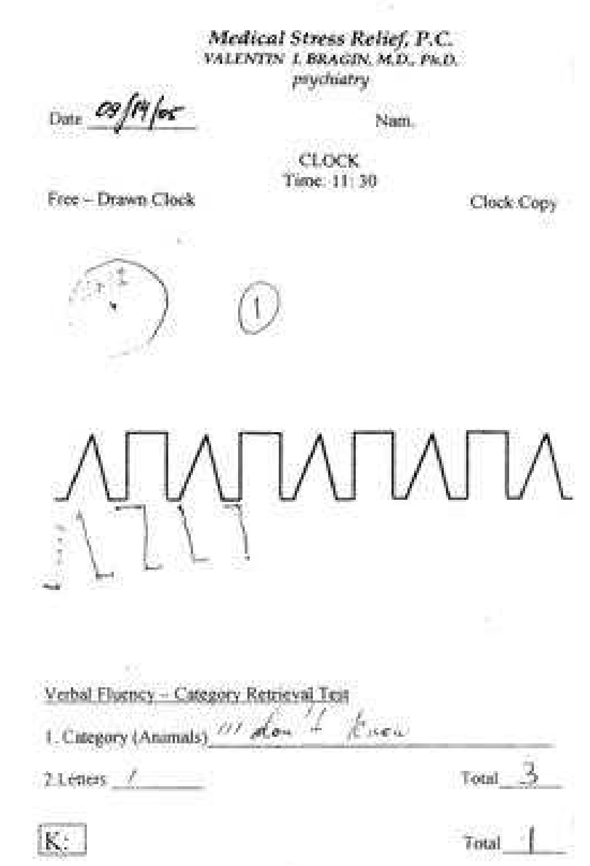

Figure 4

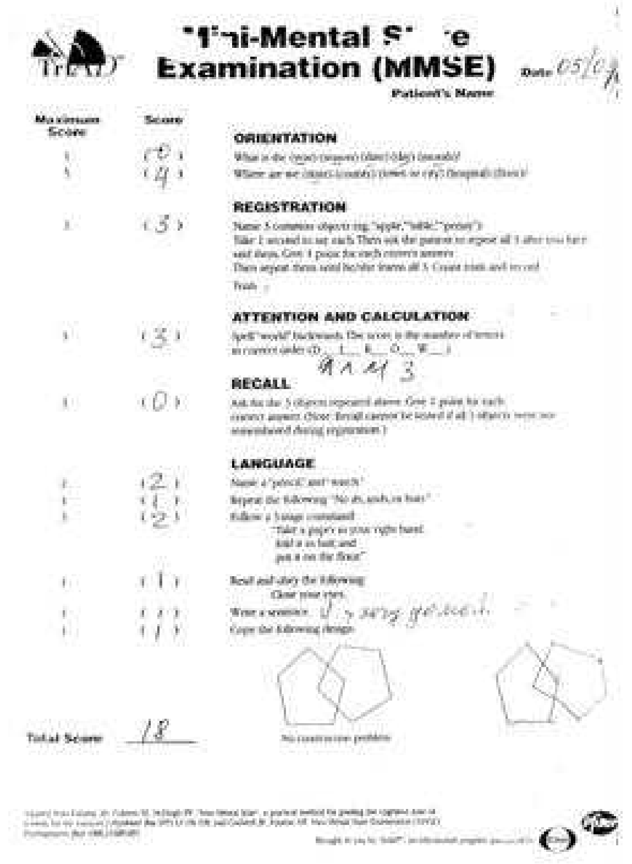

Figure 5

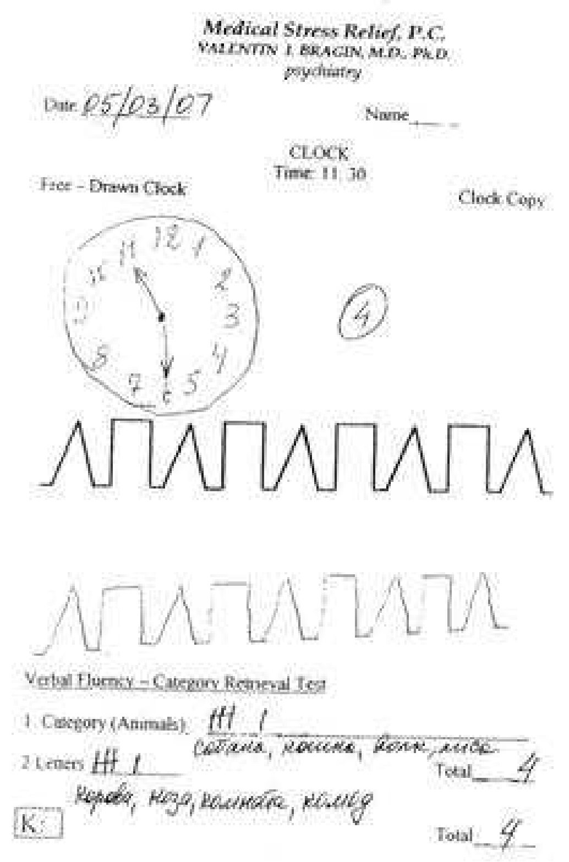

Figure 6

Discussion

Many people think, that dementia is a "whole family illness". And every family member, including the patient, is affected by dementia. The caregivers report having an experience of feeling of being overwhelmed, demoralized and perplexed. Over the time, the caregivers became increasingly frustrated, hopeless and depressed by observing ongoing patient's loss of cognitive and functional capacities. Our caregiver's Zarit Burden Scale score is 44.7 (moderate level) (8).

This program has been used with dementia patients, who are suffering from different level of cognitive decline, starting from mild memory deficit and going to severely demented homebound individuals. The results of the 24 months integrative treatment demonstrated marked improvement in brain speed, attention, and memory and frontal lobe functions (9). This year, we presented positive results of cognitive performance (case-study) during 48 months of integrative treatment (10).

Recently, it was demonstrated on SPECT scan that hand exercises increase rCBF (cerebral blood flow) in numbers of important areas in the brain (11). Based on these data, we may suggest, that the hands exercises have positive effect on brain metabolism as well.

These exercises help the caregivers to fight the stress, and to overcome frustration and anxiety as well. Improving caregiver well-being can keep patients out of nursing home placement for 18 months (12).

Conclusion

Active caregiver's involvement in a home base treatment program could benefit the caregiver as much as the patient, by helping them to combat stress, to maintain positive attitude, and to feel more peaceful and effective as a caregiver.

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Poster presented at the 15th Annual Dementia Care Conference , Chicago, USA, August 26-29, 2007