Augmentative Alternative Communication for Alzheimer's Patients and Families' using SAVION

Rakel Berenbaum M.A.
Melabev- Leader in Alzheimer Care
POB 3025, Jerusalem, Israel
972-2-52-720-3025
Melabev1@gmail.com

Yehudit Lange, O.T.,
Melabev- Leader in Alzheimer Care
POB 3025, Jerusalem, Israel
972-2-
el2002@netvision.net.il

Leah Abramowitz, MSW
Melabev-Community Clubs for Elder Care,
Melabev Institute for the Study of Aging,
POB 3025, Jerusalem, Israel
972-2-6555198
leaha@szmc.org.il

ABSTRACT

With an estimated 35.6 million people worldwide dealing with dementia, solutions must be found to ease the memory loss, mood changes and communication problems associated with these syndromes. SAVION is a computer program developed in Israel to offer cognitive stimulation for people with dementia. The program has been used for over ten years in day care centers, home care programs and private homes. Using the SAVION program during assisted training sessions raised several interesting research questions, such as: Can people with dementia learn to interact with the computer? How does using the computer affect their communication with those around them? How does the cognitive stimulation affect their self-esteem? Can computer technologies provide an additional channel of communication for caregivers to relate to people with Alzheimer's Disease and help them, and their caregivers, maintain their identity and functionality? This paper reports on some results from studying these questions. Initial results indicate that people with Alzheimer's Disease can learn to interact with the computer and that computer assisted stimulation activities did not only offer cognitive stimulation to patients with dementia, but also served as a means for the patients to communicate about their well-being with families and caregivers.

Categories and Subject Descriptors
J.4 SOCIAL AND BEHAVIORAL SCIENCES, Psychology

General Terms
Human Factors

Keywords
Keywords are your own designated keywords.

Alzheimer's Disease, Dementia, Quality of Life, cognitive

stimulation, human-computer interaction (HCI), social togetherness, communication, module for enhanced social inclusion, augmentative communication , memory aids, , AAC Acceptance, AAC Use, computers in human behavior , AAC devices, aphasia, cognitive disability, Relationships, Reminiscence,

1. INTRODUCTION
As of 2010, there are an estimated 35.6 million people with dementia worldwide. By 2050, it is projected that this figure will have increased to over 115 million [1]. Dementia is accompanied by loss of memory, mood changes and communication problems[2]. Most forms of dementia have no cure. When a person with dementia finds that their mental abilities are declining, they often feel vulnerable and in need of reassurance and support. The people closest to them - including their caregivers, friends and family health and social care professionals - need to do everything they can to help the person to retain their sense of identity and feelings of self-worth. Dealing with these progressive diseases can cause a major strain on family caregivers as well [3,4,5]. The day-to-day challenge for families and caregivers, is figuring out how to maintain the routine and normal activities that ensure a rich and quality life for the person with dementia and the rest of the family in the midst of upsetting evidence of multiple losses. [6]

Communication is the medium through which humans relate to each other in meaningful ways. Communication has been conceptualized as having four functions: (1) the expression of wants and needs, (2) information exchange, (3) maintenance of social etiquette, and (4) social closeness. Disease or disorder, especially dementia, can disrupt communicative abilities and, therefore, interpersonal relationships and functional activities. [7]

Many suggestions for improving communication between people with dementia and those around them have been proposed [8,9,10]. Augmentative and alternative communication (AAC) aids can also have an impact on the relationship between the person with Dementia and their caregiver. The goal of AAC interventions is to assist individuals with severe communication disorders to become communicatively competent. [11]. It seems unusual that a computer program developed for cognitive stimulation can act as an aid to communication. And yet it is exactly such an idea that

This research explores how computerized and culturally adapted computer activities can be used as both cognitive stimulation for the person with Dementia and as an alternative means for communication for families and caregivers with the patient. In what follows, the document presents the SAVION computer program designed especially for people with Dementia (Section

2). Section 3 describes the research study. Section 4 presents the results and section 5 the conclusions from this research.

2. SAVION

SAVION is a computer program developed for one-on-one cognitive stimulation for the person with Alzheimer's disease or other types of dementia. It was designed with an extremely simple and user-friendly interface to increase usability. It includes exercises in Math (see Figure 1), language (see figure 2), shapes (see figure 3), and memory (see figure 4). It has been used for over 10 years in Melabev's 8 day care centers and home care programs in Jerusalem - even with people who never used a computer before. At Melabev's centers there are memory clubs for people with mild dementia, and activity groups for people with more severe dementia. People from both types of groups use SAVION at Melabev and were included in this research.
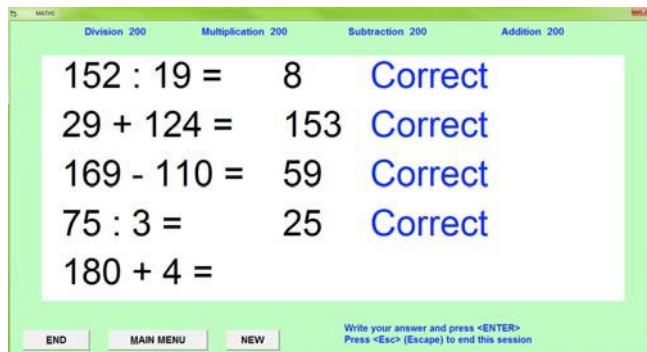

Figure 1: SAVION – Math

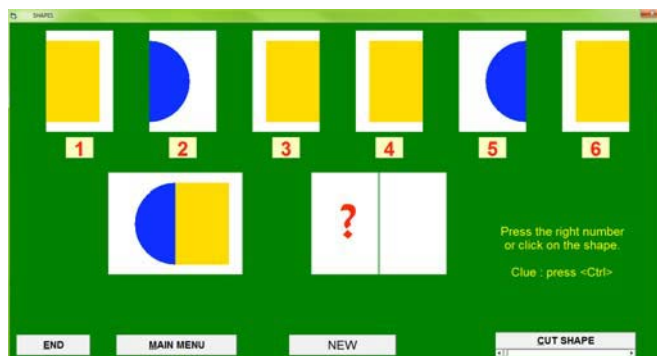**Figure 2: SAVION – Language**

Figure 3: SAVION -- Shapes

Goals of the SAVION therapy with elders with dementia include; providing cognitive stimulation in a respectful manner, increasing clients self esteem and confidence, exposing clients remaining abilities, activating the client (i.e. use of the keyboard), enabling the client to learn something new (i.e. use of the computer),

improving communication between patient and caregivers, and improving quality of life of the client. Clients sit with a trained computer activity worker at the computer for sessions of about 20 to 30 minutes each time. They are given a choice of which of the four activities they would like to work on that session and most end up working on all four. Clients might work with different activity workers on different days at the center.

Figure 4: SAVION -- Memory

When Melabev began using SAVION in their centers a form designed by the Occupational Therapist was given to the computer activity workers to fill out on each client after each computer session (Figure 5). This form was used for clinical purposes – to transfer information about each client from one activity worker to the other, to note which activity particularly interested each client, to record any decline related to the disease process, and in general to note any responses the client made in reference to their work at the computer.

MELABEV- Community Clubs for Eldercare

Occupational Therapy- Computer work follow-up

Client's name _____

WORKERS EVALUATION	CLIENTS REACTIONS
0=Unable	0=Doesn't enjoy
1=Needs a lot of help	1=Enjoys
2=needs a bit of help	2=Enjoys a lot
3=Independent	

Date	Math	Shapes	Words	Memory	Workers Evaluation	Clients Reactions	Other Comments
12.1.03	10-*20 +30		Links opposites		1	1	Had a hard time , Best at opposites
19.1.03	10- ,20x,20+		same		1	1	Better to avoid minus – can't do it any more
2.2.03	20x,20/		same		1	1-2	Was successful at all the activities and enjoyed them.
9.2.03			same		1	2	Declined, very slow, but if patient he comes up with the answers and is happy with his success

Figure 5: Sample Occupational Therapy Evaluation form

Therapists wrote down verbal comments made by the patients during the therapy sessions that related to the patients feelings toward working on the computer program, towards their abilities related to the program, and their feelings towards the therapist. They also recorded how well each patient performed at each session. No differentiation was made on the forms regarding which group the clients were members of and what severity level of dementia they had.

Often in the comments column workers would write down exact quotes from clients. These included quotes like "Oh, I didn't think my brain still works, and now I see that it does." "It is so nice working with you." "When can we do this again?"

3. Investigation

After over ten years using SAVION, it was decided to take a deeper look at the work being done by the clients at the computer. We chose to look closely at the clients spontaneous comments during their sessions using SAVION with the activity worker as well as the insights of the activity worker. These were found in the comments section of the occupational therapy evaluation forms (figure 5) which were filled out by activity workers after during and after use of SAVION. We wanted to know if there was more that could be learned about the work at the computer from the clients own comments. To this end we analyzed 80 patient's verbal responses included in evaluation forms (figure 5) at three different Melabev Alzheimer Day Care centers in Jerusalem, Israel from January 1999 to January 2009.

The 80 forms were chosen from both types of groups, those with mild dementia, and those with more severe dementia. The same kind of data was collected on the forms for each type of patients. The form did not differentiate between the types of groups, and what severity level of dementia each patient had. To try to avoid the influence of the deterioration caused by the disease, we chose to look for each patient at just one full year of work with SAVION.

We (the first and second author) independently analyzed the Occupational Therapy reports. We randomly chose the reports of 40 clients from among hundreds of client's forms. Each one of us then made a list of all the patients' direct quotes or any extra comments made by the therapists. We then compared these lists and identified recurring themes, which were coded to draw some insights.

We also rated the patients responses as positive or negative in relation to the intervention. For example if a patient stated: "Can we do this again" it was rated positive. If the client said "this is too hard for me" it was rated negative. For each client the researchers chose to look at one full year of work with SAVION (to try to avoid the influence of the deterioration caused by the disease). In addition to reviewing the forms, activity workers we interviewed activity workers and recorded their response.

4. RESULTS

Activity workers reported that over 50% of the Alzheimer's patients who never used a computer before their starting to attend daycare were able to learn how to use a regular keyboard and overcame their initial fear of the computer.

After coding the responses, we found that 90% of their comments relating to the computer work were positive. We also found that comments ca be related to seven unique categories: Who am I today? (Figure 6), Who was I in the past? (Figure 7), The influence of the Savion intervention on the emotional state and coping of the client (Figure 8) , Quality of life (Figure 9), Springboard to writing their own life history on the computer, Comments by the client about his memory, cognition, and concentration (Figure 10), Comments related to the worker/client relationship (Figure 11).

- "I'm amazed that my head still works"
- "I did it!"
- We discussed associations between her name and the words in the word list
- "Wow, I know it all"
- "I'm already old."
- She acted like I was the student and she was the teacher

Figure 6: Who am I Today?

- She connected our work to her experiences during the Holocaust and said that her words our part of our history
- "Today I want to write about my step mother so people will know that step mothers can be good – mine was"
- "All this I learned in school and I see that it helps me"
- " I was Ben Gurion's body guard"

Figure 7: Who I was in the Past

- He was very sleepy in the group, but woke up to work at the computer
- He left the computer happy though he came in very upset
- She left the group agitated but after working at the computer she calmed down

Figure 8: Emotional state and coping of client

- "Today I was successful – it made me feel good"
- "This is so nice – I like learning new things"
- " I enjoy this so much I don't want to leave"
- She is very unsure of herself and needs a lot of encouragement.

Figure 9: Quality of Life

- " I'm happy to see that my mind still works – I was afraid it stopped"
- ' One must exercise their mind so it doesn't go to sleep"
- She asked: "What does this do for my mind" I want to do real hard problems.
- With the shapes she said her mind was "getting mixed up"

Figure 10: Memory, Cognition, Concentration

- "Thank you for helping me exercise my mind – it's so important"
- " There aren't so many people who have the patience to do this with me"
- She was happy to see me and asked to work first
- She liked the interaction with me
- "You have given me hope"
- When doing the shapes she was afraid that I was testing her

Figure 11: Interaction with the activity worker

Once clients got over their initial fear of the computer and their successes at SAVION helped them learn how to interact with the computer and the computer worker, many of them wanted to write their life histories at the computer. This they did together with the activity worker.

5. CONCLUSIONS

Use of SAVION has positive effects on the client's quality of life. The therapeutic use of the program also has positive effects on memory. Most clients are able to learn how to interact with a computer. The client realizes that he still can remember certain

things and how to do certain things. Being at the computer with the activity worker is an opportunity for communication and a lot of positive communication takes place. The patient is able to see his strengths. More research is needed in this area to further understand all the benefits of cognitive training at the computer with the Alzheimer's population and how they can provide an alternative communication means for caregivers to relate to people with Dementia and help them and us maintain their identity and functionality.

6. ACKNOWLEDGMENTS

7. REFERENCES

[1] Wimo, A., Prince, M. 2009. *World Alzheimer Report.- Executive Summary*, Alzheimer's Disease International.

[2] MacInnes, N. 2011. *Alzheimer Society factsheet- Dementia.* Alzheimer's Society, England. Tavel, P. 2007. *Modeling and Simulation Design*. AK Peters Ltd., Natick, MA.

[3] Ory, M. G.; Yee, J. L.; Tennstedt, S. L.; Schulz, R.(Ed) 2000. The extent and impact of dementia care: Unique challenges experienced by family caregivers. In Schulz, R.(Ed) . Handbook on dementia caregiving: Evidence-based interventions for family caregivers.

[4] Zarit, S.H, Reever, K.E., Bach-Peterson, J. 1980 . Relatives Of The impaired elderly: correlates of feelings of burden. *Gerontologist*. 20: 649-655.

[5] Rabins, PV, Mace, NL, Lucas, MJ. 1982. The impact of dementia on the family. *JAMA*;248:33-335.

[6] Bourgeois, M. 2002 "Where Is My Wife and When Am I Going Home?" The Challenge of Communicating with Persons with Dementia. *Alzheimer's Care Quarterly*: 3(2) : 132-144, Spring 2002.

[7] Bourgeois, M.., Dijkstra, K., Burgio, L and Allen-Burge, R. 2001. Memory aids as an augmentative and alternative communication strategy for nursing home residents with dementia. *Augmentative and Alternative communication*, 17(3):196-210.

[8] Ripich, D.N. 1998. Functional communication with AD patients: A Caregiver training program . *Alzheimer Disease and Associated Disorders*, 8(3):95-109 ,

[9] Cohen- Mansfield, J. 2000. Nonpharmacological management of behavior problems in dementia: The TREA model. *Alzheimer's Care Quarterly*, 1(4):22-34.

[10] D. Golan. 2010. Effective communication with Alzheimer's patients. In Alzheimer and other Dementias. Treating and Coping with Mentally Frail in the Community. Pages 62-73 Rakel Berenbaum (ed). Eshel & Melabev: Jerusalem, Israel.