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Computerized personal intervention of reminiscence therapy for Alzheimer's patients

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ABSTRACT
The aim of our study is to determine the efficacy of a personalized multimedia system developed for use by patients and their caregivers in the treatment of mild Alzheimer's disease (AD).

We have designed and developed a prototypical system and conducted a pilot study in order to examine the feasibility of using a personalized reminiscence system and evaluated its acceptability by patients and caregivers in Israel [1].

Results from the pilot study indicate high satisfaction levels from those using the system as well as a strong tendency towards repeated use. There was also a clear preference for personal rather than general material when both were available. Based on these initial positive results with the prototypical system we are now in the process of designing a large scale study to further evaluate this system.

The research plan described here involves a collaborative effort involving two projects utilizing behavioral interventions based on computerized systems for patients with AD (personalized reminiscence therapy and cognitive training).

The reminiscence project which is the focus of this paper has two objectives: (1) Developing a personalized reminiscence system, which will enable independent use and administration for both patients and caregivers. (2) Evaluating the contribution of the system to the cognitive functioning and well-being of AD patients and its effects on family members and caregivers.

Categories and Subject Descriptors
H.5.2 [Information Interfaces and Presentation]: *User Interfaces – Evaluation/methodology, Screen design, User-centered design*; J.3. [Computer Applications]: *Life and Medical Sciences – Health*.

General Terms
Design, Experimentation, Human Factors.

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Alzheimer's disease, dementia, reminiscence therapy, multimedia, user-centered design, human computer interaction, rehabilitation engineering, computerized cognitive training.

1. INTRODUCTION
Alzheimer's Disease (AD) is a degenerative brain disease that gradually destroys a person's brain cells and causes a progressive decline in cognitive function. AD is the most common form of dementia (more than 50% according to [2]), a clinical syndrome resulting from brain damage. AD patients experience a decline in the areas of memory, attention, language, communication, problem solving and reasoning. Life expectancy from the onset of the disease is 8-10 years on average. More than 24.3 million people are currently estimated to have dementia, and 4.6 million new cases are diagnosed each year (one new case every 7 seconds). The number of people affected is expected to double every 20 years to 81.1 million by 2040 [3].

AD does not only affect the patient, but as the disease progresses patients become increasingly dependent on others in many aspects, such as performing activities of daily living, caring for their health and maintaining their welfare. The primary burden of support for the patient usually falls on one person who takes on the role of caregiver. Green and Brodaty [4] describe four factors influencing caregiver's burden, namely psychological, physical, social and financial. Psychological effects include general distress [5, 6] and depression [7, 8, 9]. Physical effects result in poorer physical health of caregivers comparing to non-caregivers [10]. Caregivers also experience social isolation because of the caregiving role [6]. Also, there is a considerable financial strain on the caregivers as a result of the costs of care [4].

Currently there is no cure for AD. The available therapeutic options include drugs, psychosocial and lifestyle interventions in order to relieve both cognitive and behavioral symptoms. Pharmacological interventions have limited efficacy and are, at best, symptomatic [11, 12, 13]. Studies have demonstrated that psychosocial treatments are able to decrease deterioration in patients' condition [14]. One of the most common psychosocial treatments used in Alzheimer and elderly care is reminiscence therapy. It is intended to stimulate the patients' long-term memory (a capability that is relatively preserved in AD patients compared

to short-term memory) and to enable conversations by using a variety of tangible familiar stimulations. Reminiscence therapy can decrease depression symptoms, facilitate social involvement and encourage participants to evaluate their lives and achievements [15,16].

To date, there is no clear evidence regarding the effect of reminiscence therapy on cognitive function. Some studies did not demonstrate a significant improvement [17, 18], possibly related to methodological issues. For example: Goldwasser, Auerbach & Harkins [19] studied the cognitive, affective and behavioral effects of reminiscence group therapy on demented elderly patients and found a slight but insignificant improvement in cognitive status. They concluded that a more sensitive assessment tool is required for evaluating short term changes in cognitive status than the Mini-Mental Status Examination (MMSE) which was used in their study. Similarly, while Thorgrimsen, Schweitzer & Orrel [20] conducted a pilot study to evaluate the effects of reminiscence in people with dementia, they found that the MMSE score of people attending the reminiscence group was almost identical after 20 weeks while the control group scored almost 4 points less, yet this difference did not reach statistical significance. They thus concluded that as significant results are more difficult to obtain with a limited number of participants, a multicentered randomised controlled trial is needed to confirm the positive trend that they reported.

Nevertheless, certain studies did find significant improvement in cognitive function due to reminiscence therapy. Baines, Saxby & Ehler [21] compared reminiscence and reality orientation (RO) therapies and found an improvement in cognitive function only for the group of participants who received RO therapy prior to receiving reminiscence therapy. Also, a more recent study [22] evaluated the effect of life review (a more structured type of reminiscence therapy) among people with mild to moderate dementia. The study found that, compared to a control group, patients under the life review treatment had better results in terms of cognitive measure (MMSE), depression level, mood and communication.

Increasingly, computerized systems are being designed for therapeutic treatment of Alzheimer patients. Most of these systems address the cognitive decline of the patients by trying to compensate for the loss [23] or to offer a cognitive training [24]. Lately, there is a growing trend towards the design of Web sites for Alzheimer's patients [25, 26] and of computer systems for the purpose of psychosocial treatments in Alzheimer care [27, 28].

A notable landmark in the efforts to provide computerized support for therapeutic treatment of AD is project CIRCA (Computer Interactive Reminiscence and Conversation Aid). The project was designed in Scotland as a multimedia conversation aid system, which addresses the challenge of supporting reminiscence therapy by using contemporary technologies to provide a computer-based, user friendly alternative to the traditional process. The project had success in prompting conversations, in promoting more natural and more relaxed atmosphere, and in allowing the patients to interact with the system [29]. More recently, a project of creating personalized multimedia systems was initiated in Baycrest in Canada [30].

We have designed a collaborative study involving two projects utilizing behavioral interventions based on computerized systems for patients with AD. We aim to evaluate the efficacy of treating patients with mild AD by means of either personalized computerized reminiscence therapy or computerized cognitive training as compared to controls using the Mindstreams (NeuroTrax Corp., NJ) computerized neuropsychological assessment instrument [31] as the cognitive outcome measure. Within this broader framework, this paper focuses specifically on the personalized reminiscence system.

The reminiscence system research has two objectives:

(1) To develop a personalized computerized reminiscence system, allowing for independent use and administration of both patients and caregivers. The importance of a personalized system is especially salient in immigrant or in highly mobile societies, due to the heterogeneous background of the patients. This is reflected by the variety of locations, events and languages that can promote reminiscing in AD patients in these societies. Moreover, patient-adapted external aids in dementia care are considered more effective, because they better meet the patients' capabilities and needs [28, 32, 33] and increase their motivation [24].

(2) To evaluate the contribution of the system on cognitive function in patients with AD, as well as on patient well-being, and its effects on family members and caregivers.

2. Preliminary Results

We have developed a prototypical system and conducted a pilot study in order to examine the feasibility of our personalized reminiscence system and its acceptability by patients and caregivers in Israel [1]. Our system improved upon existing systems (see above) in several ways. Unlike Baycrest's study, we concentrated on open-ended, extensive personal content rather than on predefined life stories. In addition, we developed a web-based system with a more flexible and intuitive user interface including a touch screen as the input device – rather than a remote control. This technology was similar to the one used in the CIRCA project. However, whereas CIRCA included only general content, our system also included personalized content according to patients' background and preferences.

The aim of the pilot study was to assess the suitability of the system for Alzheimer's patients and their caregivers. Since at that point we were interested in understanding the qualities of the interaction itself rather than the system's effects on the cognitive functioning of the patients, we used qualitative evaluation to identify relevant human interactions and processes. Our system was evaluated by 5 Alzheimer's patients from the Psychogeriatric Institute at the Tel-Aviv Sourasky Medical Center. Each patient completed 2 interactive sessions using the system with the support of a caregiver. The participants' behavior during the sessions was observed and videotaped, and interviews were conducted with the patients and the caregivers. Content analysis was performed in order to investigate the effects of the system on the patients, its usability, and the patients' satisfaction with using the system, as well as to identify any additional effects of the system on both patients and caregivers.

The results of the study indicated high user-satisfaction levels with the system and a strong tendency towards repeated use. The system was found effective in prompting conversations and in evoking personal memories; it was also helpful in facilitating patient–caregiver interaction. The results also showed a clear preference of personal over general material when both were available. Patients and caregivers alike recognized the advantage

of using the system rather than traditional reminiscence methods, since it brought together various objects into one easily accessible system and improved the patient's self esteem as a consequence of being able to use a computer.

3. Research Plan

To test the effects of the reminiscence system more rigorously, we have embarked on a research project that will be described below. The project includes the development of the system, followed by testing its effects. The research is therefore divided into 2 main phases as described below:

3.1 The system's development

This phase will concentrate on the development of the reminiscence therapy support system. The system will include 2 main components- front-end and back-end. The former component will support the interactions during the therapeutic sessions. The design of this component will be based on the prototypical system and the preliminary results described above and also on up-to-date studies describing user interfaces for Alzheimer patients and the elderly in general. The latter component will facilitate addition and update of content by caregivers and family members. The system will be developed using internet technology, which will allow the users to comfortably access it from any location (e.g., medical institutions, clubs for the elderly, or the home of the patient or family member).

The development of the system will be performed in an iterative manner. Throughout the development we will use feedback from both patients and caregivers concerning the ease of use of the system and its appropriateness for the intended user population.

3.2 Testing of the effects of the system

The effects of using the personalized reminiscence therapy support system can be divided to three aspects. The first two aspects relate to the potential effects of the system on the patients. The third aspect addresses its effect on the patients' family members and main caregivers. The following describes the main objectives of the evaluations:

3.2.1 The effect of the system on patients' cognitive function:

The objective of this study is to determine whether using the system on a regular basis improves cognitive function in patients with AD.

3.2.2 The effect of the system on patients' psychological/ behavioral well-being:

In the early stages of AD patients may suffer from personality changes, irritability, anxiety and depression [34]. In this phase of the study we will evaluate whether using the system on a regular basis improves or moderates these behavioral symptoms.

3.2.3 The effect of the system on main caregivers / family members:

This evaluation is aimed at finding whether using the system on a regular basis eases the caregiver's work, reduces the burden on family members, or has any other effect on patient-caregiver and patient-family relations.

4. Methods

4.1 Patient sample

A total of 150 patients (50 patients in each group) with Alzheimer's disease according to DSM-IV criteria residing in assisted living facilities will participate in this study. The inclusion criteria will be: age (sixty years old and above) and mild stage of the disease (according to the Clinical Dementia Rating Scale). The exclusion criteria will be: visual and auditory impairments or any other physical impairment which may prevent the participants from using the computerized systems used in this study.

The participants will undergo a preliminary assessment in order to determine the stage of their illness. The assessment will be performed by the staff of a multidisciplinary Memory Clinic at the Beersheva Mental Health Center and will include a medical, cognitive and functional assessment using the following instruments:

- Mini-Mental State Examination for cognitive screening [35].
- Clock Drawing test for cognitive screening [36].
- Lawton and Brody's Instrumental Activities of Daily Living (IADL) for assessing functional capabilities [37].
- Clinical Dementia Rating (CDR) scale as a global measure rating the severity of dementia [38].
- Mindstreams computerized cognitive assessment battery [31].

4.2 Experimental Design

The participants will be assigned randomly to one of the following 3 treatment groups:

1. Personal reminiscence therapy (using the computerized reminiscence system with personal contents for each participant)

2. Cognitive training (using the Savion software program [Melabev, Jerusalem]).

3. No treatment – This group will receive neither the above interventions nor any other similar interventions. In order to overcome possible Hawthorne effect, the participants in this group will be meeting a caregiver for a personal discussion of current events. This will ensure that the participants in this group are given personal attention of a different nature to the other two treatments.

4.3 Procedure

Patients receiving reminiscence therapy as well as those using the cognitive training program will participate in 2 – 3 sessions a week, each of 30-minutes duration over a period of 6 months,

supervised by a caregiver or research assistant. Each of the participants in the control group will meet a caregiver or research assistant for the same frequency to discuss current events. Taking the rate of recruitment into account, the study is expected to continue for a period of up to two years.

4.4 Measurements

The following describes the measurements that will be used in our research:

4.4.1 Cognitive function assessment

The participants' cognitive function will be measured by the Mindstreams computerized testing battery. The assessment will be done at baseline, at one month, at 3 months and at study termination (t, t+1, t+3, and t+6). This will allow us to evaluate the efficacy of the interventions compared to controls with regard to cognitive function.

4.4.2 Patients' psychological/ behavioral well-being

To assess behavioral outcomes we will use the NPI - Neuropsychiatric Inventory [39]. In addition we will use the Dementia Quality of Life (DQoL) instrument [40] to assess quality of life of the patients.

We will also conduct a qualitative assessment to find additional effects of the system on the patients. The qualitative methods will include observations during the use of the system, interviews with the patients at various stages during the research and interviews with caregivers and family members during the course of the research and at its completion. The qualitative assessment will concentrate on a sample of 8 participants.

4.4.3 Caregiver's burden

For the assessment of caregivers' burden and psychological morbidity we will use the Zarit Caregiver Burden Interview [41].

In addition we will conduct qualitative assessment to evaluate changes in patient-caregiver relations. The qualitative assessment will include interviews with the main caregivers/ family members during the course of the research and at its completion. The qualitative assessment will concentrate on a sample of 8 participants and their main caregivers.

5. Data Analysis

Group means will be evaluated using a two-way analysis of variance (ANOVA) with experimental group as a between-groups factor, and with repeated measures of the dependent variables according to the table below:

Table 1. Experimental groups

Experimental group	**baseline**	**1 month**	**3 months**	**6 months**
Cognitive training	CFA	CFA	CFA	CFA
Reminiscence therapy	CFA, N-D, Z	CFA, N-D, Z	CFA, N-D, Z	CFA, N-D, Z
Control	CFA, N-D, Z	CFA, N-D, Z	CFA, N-D, Z	CFA, N-D, Z

CFA: Cognitive Training Assessment

N-D: Neuropsychiatric Inventory (NPI), Dementia Quality of Life (DQoL)

Z: Zarit Caregiver Burden Interview

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