Enabling Biographical Cognitive Stimulation for People with Dementia

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Abstract
Non-pharmacological interventions are the most common and arguably most effective for people with dementia. Some of these approaches have been proven to benefit from the usage of biographical or personalized materials. These contents are not always easy to obtain. Alongside, it is a challenge to maintain awareness of what is meaningful for a certain person. Faced with an absence of tools to collect and manage biographical materials, we created a web platform that supports the work of psychologists, streamlining the collection of relevant information about people with dementia. This knowledge is then used as a starting point to perform reminiscence and other biographical cognitive stimulation practices. In this paper, we present the design of our platform and results from a case study with one psychologist and three patients, across a period of two weeks that showed improvements in the collection of meaningful data about a person, and on maintaining awareness of the therapy as a whole.

ACM Classification Keywords
H.5.m. Information interfaces and presentation (e.g., HCI): Miscellaneous

Introduction
Dementia is a general term that describes a wide range of symptoms involving a decline of memory, language,

reasoning and other cognitive skills that affects a person's ability to perform everyday activities. There are worldwide approximately 47 million people living with dementia and this number will almost double every 20 years, reaching more than 131 million in 2050 [6]. Once there is no effective treatment, the goal of experts is to slow down its evolution by pharmacological (with limited impact) or non-pharmacological interventions. There are several non-pharmacological approaches [1], however our focus was reminiscence therapy, which uses pictures, keepsakes or music to motivate the discussion and elicit memories that people with dementia have from their past. In addition, another of our goals was to use those personalized or biographical materials in broader contexts than reminiscence therapy, namely in biographical cognitive stimulation activities, which involves performing recreational activities such as problem-solving or puzzles.

Usually, these activities are carried out by psychologists. Often, these professionals end up not having enough information about the past of the person with dementia, leading to a lack of materials. Consequently, this reduces the number of discussion topics during reminiscence therapy and forces psychologists to perform cognitive stimulation activities with generic materials, which ultimately may reduce their effectiveness.

Several projects have been created about dementia and its non-pharmacological approaches. Regarding reminiscence therapy, some have explored the presentation of multimedia to prompt memories and elicit communication (e.g., [3]). Other examples include multimedia biographies and virtual reality tools that seek to immerse people in virtual worlds eliciting them to communicate about their past [4]. However, part of these approaches tend to be costly time-wise (personalized video biographies) or are not scalable (virtual reality tools). While biographical content is used in some reminiscence tools, these have not been explored in cognitive stimulation [2], despite being generally accepted that emotion plays a positive role in the response to therapy. Overall, there is a lack of tools to support the role of the psychologist namely in the automatic gathering of biographical, personalized and generic materials. Further, this gap extends to the deployment of the therapy with an absence of tools to support the psychologist in delivering therapy across several sessions.

We present a web application, Scrapbook, which supports the work of psychologists, helping them to perform reminiscence and cognitive stimulation therapy, allowing an agile collection of contents about the person with dementia and a clinical follow-up over time. Feeding personalized data into the platform can be done by the psychologist (e.g., inputting keywords that are representative of the patients' life, like his/her hometown and interests, which sparks an automatic collection of data from web services), or by family/friends through a friendsourcing mechanism (e.g., through a social network or custom application) [5]. The platform then allows the creation and deployment of therapy sessions, with pre-selected contents, saving feedback about particular contents (which generates further collection of data), and visualization of this data. A 2-week case study with one psychologist and three patients was performed to evaluate the acceptance, usefulness and perceived effectiveness of Scrapbook by psychologists and people

Figure 1: Workflow of the system (registration) - a meeting is held between the psychologist and a caregiver (or the patient) to register seed biographical information; then, the psychologist can begin the sessions with the patient.

with dementia. Results showed that our tool came to fill a gap in current therapy procedures, leading to an unexpected increase of knowledge about the patients in a short period, and in several memorable responses.

Preliminary Studies

To understand the current practices, needs and problems of those involved with dementia, we began by interviewing 11 health professionals from different areas (9 psychologists, 1 nurse and 1 occupational therapist). These interviews were subjected to a thematic analysis, with a mixed coding approach.

As a result, we can point out some of the main problems for health professionals, such as the collection of personal material needed for reminiscence therapy. Primary caregivers can show mistrust and lack of initiative to provide pictures, objects or other type of material to the clinical team. This difficulty leads to a lack of information of daycare centers and nursing homes about the people they care for.

Another problem is the complexity of storing all the objects used in the therapies, such as photographs, keepsakes or notebooks with activities, leading to the existence of many files and bags with materials.

Regarding the introduction of technology in their activities, they point out that new technologies are not used as often as they would like partly because they are time-consuming. Still, when possible they recur to platforms like YouTube and Google StreetView. Psychologists have the expectation to have records and statistical graphs, to help them do a better assessment of the progression of therapy and the patients' condition.

Digital Scrapbooks

We developed a web application, optimized for personal computers and tablets, which works as an online shared digital scrapbook. The information and materials recovered from the constructed scrapbook are used by the psychologist to perform reminiscence therapy and cognitive stimulation activities. The following subsections describe in detail the operation of the system. Figures 1 and 2 represent a system overview, and the way the different stakeholders interact with it.

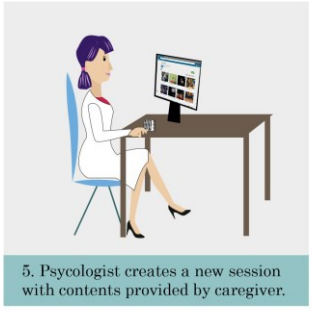
Registration of people with dementia

To be able to perform activities with a person with dementia, the psychologist must first register her in the system. At this stage, the psychologist must enter, preferably with the help of a caregiver, personal data of the person with dementia, namely her interests (Cinema, Food, Hobbies, Literature, Music, Politics, Religion, Sport), relevant places, personal photographs or videos, life events (such as marriage) and relatives (entering the name, degree of kinship and photographs). If the person with dementia has a Facebook profile, or if the relatives contribute with information to create a new profile, the registration form can be automatically filled out. In addition, they can define the person's online caregivers, who will be responsible for validating materials collected through Facebook posts (only validated materials are collected).

Creating a session

For each one of the relevant interests and places collected through registration process, the system collects a pre-defined number of photographs and videos, from Flickr and YouTube APIs, and makes these personalized materials available to the psychologist to be used in the sessions.

4. At home, the caregiver provides new contents for therapy.



5. Psycologist creates a new session with contents provided by caregiver.

6. Reminiscence therapy session with the patient.

Figure 2: Workflow of the system (feedback) - knowing the best materials used, the system asks to the Facebook network of the patient to provide similar materials. Caregiver's responsibility, is to validate the materials that the system will collect for the psychologist.

As such, before each session, the psychologist may select the materials to use and, optionally, the order in which they appear.

Reminiscence therapy

Reminiscence therapy is presented by a slideshow of photographs, videos and texts, representing subjects to be discussed between the psychologist and the person with dementia. For each one of the presented materials, the psychologist can provide feedback (for instance, based on the person's reaction) or input personal notes.

Cognitive stimulation activities

The system provides three types of cognitive stimulation activities. The Jigsaw puzzle, where a photograph is divided into several pieces and the person must drag these pieces to the correct positions; memory flashcards, where several photographs are turned upside down and the patient must flip the photos, one by one, until she finds all the pairs; and, street view navigation, where the patient can navigate through points of interest of each one of the relevant places of her life. Figure 3 presents the activities provided by our system.

Continuous growth of meaningful available materials

The main goal of Scrapbook is to increase the range and quality of available materials to psychologists, and for that, it encourages psychologists to provide feedback about the materials. When the feedback is positive, new photographs and videos are recovered from Flickr API and YouTube API, and the system interacts, through Facebook posts, with the patient's friends asking them to provide similar materials. These are then delivered to the psychologist after caregivers' validation (using the like button). Furthermore, the system also uses this social mechanism to ask for materials about subjects that it could not get from Flickr API, as well as to ask for life stories about the person told by Facebook friends and used as therapy material.

Clinical follow-up

One of the expectations of psychologists is to have something that allows them to record the results of the sessions and the evolution of the disease. Our system records every interaction during the sessions, such as the session length, the quantity of materials used, how long the material was on, or the feedback about that material. With this information, the system allows the psychologist to visualize all the events of the sessions over time. In addition, the psychologist has the option to associate notes with materials or sessions which, once registered in the system, can be repeated.

Preliminary Results

We conducted a two-week study, with one psychologist and three people diagnosed with dementia, to evaluate the acceptance, usefulness and perceived effectiveness of Scrapbook. We focused in understanding how do people with dementia respond to a digitally-supported cognitive stimulation apparatus, how do psychologists cope and benefit from a digital tool to support therapy, and to analyze if a digital tool can improve current therapy practices. Additionally, we wanted to understand how psychologists interact with the platform, and to assess its user experience. The social mechanism, where caregivers can contribute with materials, was not included in this study.

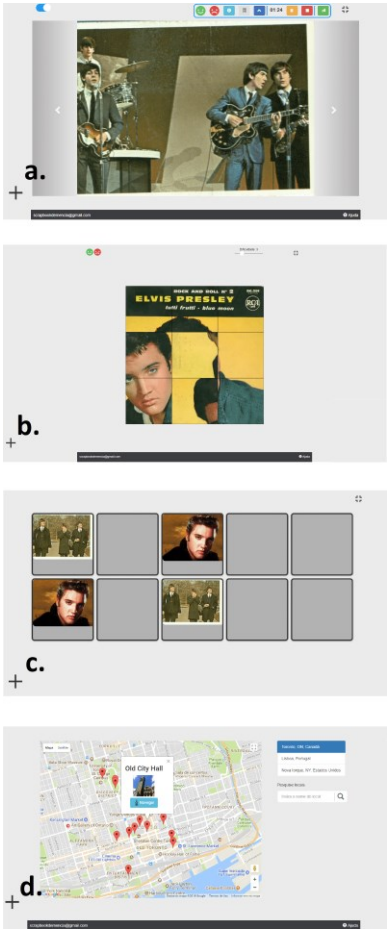


Figure 3: Scrapbook's non-pharmacological activities: **(a)** reminiscence therapy, **(b)** jigsaw puzzle, **(c)** memory flashcard, **(d)** street view navigation.

Before the beginning of the study, we met with the psychologist to perform a semi-structured interview about the cognitive stimulation practices, and to present and explain the usage of Scrapbook. During week one and two, the psychologist conducted at least one session with each of the three people with dementia. The schedule of the sessions and its organization was responsibility of the psychologist. At the end of the study, a semi-structured interview was performed focused on understanding the psychologist's interaction with Scrapbook, namely concerns, acceptance, usefulness, effectiveness, efficiency and limitations.

During this two-week study a total of seven sessions were performed, three anamnesis sessions to register the participants with dementia, and four sessions of reminiscence therapy. These reminiscence sessions lasted on average 32 minutes, where 11 of the 18 materials presented lead to a positive reaction. Patient 1 (P1) was a female with 77 years old, patient 2 (P2) a male with 67 years old, and patient 3 (P3) a female with 80 years old.

As positive results reported by the psychologist, we have the acceptance of the platform by the involved parties. On the one hand P1, still in an early stage of Alzheimer's, enjoyed being exposed to the platform, and particularly the closeness that it created between herself and the psychologist. She enjoyed talking about subjects that she would normally not talk about, and saw the introduction of the platform as something very natural. On the other hand, P3 was an advanced stage of the disease and she was not aware of the paradigm shift of her sessions. The most positive case was the one of P2, where were reported benefits that were not expected in a period of two weeks. The fact that before this intervention he was not able to formulate a sentence, and during the session began to sing the refrain of several songs was a success. The psychologist stated that she was aware that P2 enjoyed listening to music, but once the engagement with Scrapbook was higher, they were able to explore his likings. The effects on the attention and focus were also reported. Before using Scrapbook, the psychologist could not motivate the patient to be seated long enough to perform the sessions, and with Scrapbook, P2 sat down and observed the contents carefully. In addition, the psychologist also reported an improvement in the level of apathy and ambulation.

Furthermore, an approximation between psychologist and participants with dementia was perceptible. With the use of the platform and the increase of the amount of biographical and personalized contents, there was more material to work individually, allowing them to talk about subjects they did not normally talk about. Moreover, anamnesis sessions with relatives, which without Scrapbook would not have happened so early, led the psychologist to know her patients better, namely P3 where she reported that now she sees a "completely different person".

It was also interesting to note the acceptance of caregivers about the use of the platform, as well as the increase of collaboration and sharing of information between psychologist and caregivers.

Regarding the technical aspects of the use of the platform, the results are promising. The psychologist was very pleased with the design of the interface, and no significant usability issues were reported, namely

regarding navigation between the different menus and, most importantly, registration, preparation and execution of the session. Another of our concerns was the quality of the contents, but the psychologist ensured that she could have at least an item with quality for each theme. Additionally, despite initially being unwilling to register sensitive information online, she found useful, to be able to take notes and insert reactions about the materials during the session.

Future Work

Scrapbook can be enriched in several ways such as the creation of a caregiver's account, where it becomes possible for the psychologist to send homework to the person with dementia, the possibility of performing group sessions, where the system would be able to find common interests among all people with dementia participating in the session, or the integration of new biographical cognitive stimulation activities

Conclusions

The greatest difficulty for psychologists who want to perform reminiscence therapy is to gather material to work with people with dementia. Furthermore, cognitive stimulation activities, such as puzzles, performed with biographical materials are arguably more effective than those performed with generic materials. The tool presented in this paper allows for a more agile and iterative gathering of biographical knowledge and provides opportunity for a greater awareness on the deployment of a personalized therapy. Preliminary results suggest that these tools can improve the effectiveness of sessions without sacrificing the time of the psychologists.

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