

Designing Personalized Therapy Tools for People with Dementia

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Abstract

Non-pharmacological interventions for people with dementia benefit from the usage of personalized materials. These are not always easy to obtain. In a set of formative studies, we looked at how clinical staff and families recur to the usage of biographical elements to stimulate and foster the self-identity of people with dementia. Results showed that these stakeholders cherish biographically-rich information although it is often hard to obtain relevant materials. We present the iterative design of Scrapbook, a web platform that supports psychologists in the process of collecting meaningful information about a person, and applying it in reminiscence and cognitive stimulation sessions. A 3-phase deployment in a clinical setting allowed us to evolve the platform to respond to stakeholder requirements. Findings include a positive view of the developed features (e.g., biography-enriched games, caregiver app, group therapy) but also an underwhelming usage of the platform. We discuss the adoption, usage patterns, and feedback collected from clinicians, seeking to inform the design of personalized, i.e. biographically-rich, tools for therapy settings.

CCS Concepts • **Human-centered computing** → **Empirical studies in interaction design; Accessibility technologies.**

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W4A '19, May 13–15, 2019, San Francisco, NY, USA

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ACM ISBN 978-1-4503-6716-5/19/05...\$15.00

<https://doi.org/10.1145/3315002.3317571>

Keywords Personalization, Cognitive Stimulation, Dementia

ACM Reference Format:

Sérgio Alves, Filipa Brito, Andreia Cordeiro, Luís Carriço, and Tiago Guerreiro. 2019. Designing Personalized Therapy Tools for People with Dementia. In *Web For All 2019 Personalization - Personalizing the Web (W4A '19), May 13–15, 2019, San Francisco, NY, USA*. ACM, New York, NY, USA, 10 pages. <https://doi.org/10.1145/3315002.3317571>

1 Introduction

Non-pharmacological interventions for people with dementia benefit from the usage of biographical or personalized materials [21]. Life stories have been shown to have a positive influence on the quality of life of patients, their relatives, and staff [8]. Sharing information between staff and caregivers contribute to the “maintenance of the person with dementia as a whole person rather than a demented patient”, and to help informal caregivers to better accept the disease, and formal caregivers to better understand who is at their care [2, 10]. However, involving relatives can be difficult and personalized materials are not always easy to obtain.

Cognitive stimulation and reminiscence therapy are two of the most common non-pharmacological approaches. Usually, these activities are carried out by psychologists. Previous works showed that digital tools can play an important role in providing a more naturalistic interaction between stakeholders, eliciting patients’ memories, and improving the levels of apathy and self-identity of patients [7, 14]. Additionally, previous work suggests people enjoy physically interacting with digital systems and prefer their life storybooks in digital form [22].

We report the design of a digital platform, Scrapbook, that supports psychologists in deploying cognitive stimulation, by using customized biographically-rich materials (Figure 1). First, we performed a set of formative studies with nine health professionals (interviews) and 531 informal caregivers (online surveys) to understand how personal information

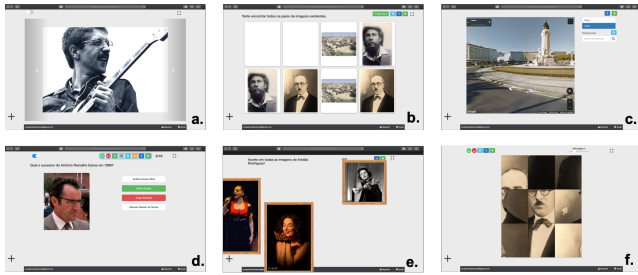


Figure 1. Main cognitive stimulation activities of Scrapbook. a. Reminiscence therapy (session control buttons hidden); b. Flashcard; c. Street View navigation; d. Quiz; e. Touch; f. Puzzle (in fullscreen).

is being collected, used, and shared among stakeholders today to improve the person’s wellbeing, in and out of clinical contexts. Results showed that all stakeholders cherish these meaningful materials, but most times they are scarce, particularly in clinical contexts.

Scrapbook is a web application to support the work of psychologists, allowing them to perform cognitive stimulation activities with biographical materials (e.g., pictures, videos, music, texts) collected agilely. Feeding personalized data into the platform can be done by psychologists (e.g., inputting keywords that are representative of the patient’s life and interests, which sparks automatic collection of further data from web services), or by family/friends through a mobile application. Additionally to the creation and deployment of therapy sessions, Scrapbook helps psychologists to maintain an overall awareness of session history. Feedback provided by psychologists about a particular material generates further collection of data, contributing to a selective improvement of the awareness of a person’s interests. Seeking to increase the involvement of informal caregivers in therapy and improve the personalization of materials, session results and response to presented elements can be shared with them through a specialized app, that can also be used by them to feed back materials to the psychologist.

Scrapbook was developed and evaluated iteratively in clinical settings, over three deployment phases. In total, the platform was used by four clinicians (three psychologists and one assistant) and 26 patients, totalling approximately seven months of use in real clinical environments.

The main contribution of this paper is the design and qualitative evaluation of a platform that allows an agile collection of materials about a person, and the usage of these materials in various cognitive stimulation activities. We provide a starting point for research exploring the involvement of caregivers in personalized therapy. Results suggest that Scrapbook improved the collection of meaningful data about a person, helped maintaining awareness of the therapy as a whole, and contributed to increase the engagement of patients and caregivers in therapy.

2 Related Work

There has been a variety of technologies developed to assist people with dementia and their caregivers [9, 11] in day to day activities, addressing safety [20], perceived safety [18], support for memory [5, 17], and support for social contact [15, 24]. In this research, we were particularly focused in understanding how people with dementia, caregivers, and health professionals are supported by technology towards improving therapy.

Several projects have sought to support reminiscence therapy, defined as the act or process of recalling the past [12] normally by “using artifacts to unleash memories and prompt conversation for present benefit” [3]. Reminiscence therapy can be performed with generic or personalized materials.

CIRCA [7] and PhotoStroller [6] are two examples of computer programs that use generic materials, meaning multimedia contents (i.e. pictures, videos, music), which, a priori, have no personal relation with the patient (e.g. famous people), to perform reminiscence therapy. In both studies, authors reported that these tools were well accepted by patients, and helped them to feel entertained and to prompt several memories.

Based on materials of significant life events, researchers have explored DVD-based multimedia biographies [2, 4], showing that these DVDs, which may take several weeks to be constructed, can positively stimulate the memory of people with dementia and improve their quality of life. Additionally, the process of creating the DVDs was enjoyable by caregivers and people with dementia, and allowed relatives to remember who that person once was and to better accept the disease. Formal caregivers also reported that this process helped them to better understand who is at their care. Subramaniam et al. [22] converted the traditional scrapbooks of six people with dementia to the digital format, showing that most of the participants preferred their scrapbook in digital form. Five participants also showed improvements in quality of life and autobiographical memory.

The use of personalized materials may significantly increase the available contents for non-pharmacological interventions. Each information (e.g., hometown, profession) about a person can be multiplied by dozens of contents. Sarne-Fleischmann et al. [19] created a system that uses generic and personalized contents (manually inserted), according to the background and preferences of patients, to perform reminiscence therapy. Results of a pilot study showed that the system can be effective in prompting conversations and in evoking personal memories. Additionally, users demonstrated a preference of personal over generic material when both were available.

While several digital tools focus on reminiscence therapy or cognitive stimulation, there has been limited effort in understanding how these activities can be deployed and supported in a clinical or care environment [23].

3 Understanding Current Practices

Our first goal towards designing a platform to support personalized cognitive stimulation in clinical settings was to understand how these activities are currently being performed, the type of materials used, how they are gathered and improved, and how caregivers are involved and interact with clinicians. To do so, we performed interviews with clinical staff followed by questionnaires to informal caregivers.

3.1 Methodology and Participants

We conducted nine semi-structured interviews with seven psychologists, one nurse and one occupational therapist. Participants worked in different contexts, from nursing homes to day care centres, or even in their own office. Questions asked were as homogeneous as they could although we took in consideration the background of each professional, leaving space for them to elaborate the aspects that are more meaningful to them. We focused mainly on their routines during appointments, what kind of tools they use and how do they exchange information between the different stakeholders, clinical or not. We complemented our knowledge, particularly pertaining the communication between stakeholders by performing an online survey to informal caregivers. We received 531 valid responses, 86.6% female, with 80.8% having a high school degree or higher, probably result of being an online survey, which should be considered when interpreting the results.

3.2 Findings

We summarily present the integrated findings of these studies, that informed the design of our platform, with focus on aspects that pertain to personalized information, therapy, and communication between stakeholders.

Person-Centred Care. Probably the most important concept raised during these interviews is putting the person in the centre of care, making all the work done focus on their wellbeing, granting that everyone can still see the person beyond the disease. Professionals emphasized the need to perceive their strong skills and habits. It is also relevant to be aware of the surrounding environment, current and past. Professionals expressed the need to know the family structure of their patients, their interests, past jobs and crafts. Additional information is always useful, and major life events, like a wedding or the birth of a son, have a preponderant impact on a person's life story. An in-depth knowledge of those aspects of each patient would allow professionals to develop and guide activities and exercises towards their patient's singularities. As a material proof of these concerns, some of our participants showed to us life books of their care home attendees. As an example of the relevance of such knowledge, one participant mentioned:

“Someone who likes flowers, even if she can't already say that she likes flowers, will have pleasure when solving a flower-related activity” (Psychologist 1)

Activities and materials. The most referred working materials were, by far, photos. Photos are mainly associated to reminiscence, making each of those sessions as personal as they could be, allowing both the person with dementia and the family to recall their own past.

There were some discordant opinions about the timeframe that those materials should refer to. One psychologist referred that past photos are much more useful to patients since the recent memory is the first to fade away and that photos taken nowadays are useless.

“It's like a traditional photo album where the most recent photos are on the last page. As the disease evolves the album vanishes from back to front until there's only the front page left.” (Psychologist 1)

However, Psychologist 2 stated that the present is still useful and recent photos should still be used. Psychologist 2 also stated that there is not a problem if the person does not remember at all that photo, mentioning that it is a situation that the psychologists are equipped to work with. They present concerns about these contents being presented at home though, if that would be the goal of our platform. However, as expected, several (63.7%) informal caregivers reported to purposely revisit old materials to reminisce together with the person with dementia.

Other than photos, professionals also approve the use of music, which allows to work different parts of the patient's memory when comparing to reminisce through photos. However, they were not so eager to use videos. Also, some professionals make a useful use of quotidian objects, often related to their patient's life. In their nursing home, Psychologist 3 mentioned:

“Last week we did an activity with a sewing machine and tried to make her use it. It was a meaningful task because the lady was a seamstress and she ended up being capable of sewing, which meant that the procedural memory was still there.”

Informal caregivers stated to resort to personal photos (55.4%), quotidian objects (20%) and music (19.8%), among other less common materials (e.g., audio stories) to reminisce with the person with dementia. Only 21 of the caregivers, 4%, use online videos, like YouTube, to revive those past memories. Caregivers tend to focus more on recalling people (55.7%) than places or events, like the wedding or the birth of a child, with 39.6% combined (other elements like objects are residually used).

Cognitive stimulation sessions continue to rely on the traditional pencil and paper exercises and general-purpose cognitive computer programs (e.g., CogWeb). Informal caregivers also report to perform cognitive stimulation activities at home (46%), with 31.6% doing it 2-3 times a week or more, mainly using paper and pencil exercises (27.7%), or crosswords and Sudoku books (13%).

Communication between stakeholders. One of the aspects raised during the interviews was the lack of knowledge of nursing home’s staff about their own patients. Sometimes, as we were told, staff does not know much more about the patients besides the name. However, we noticed two antagonistic perspectives. On one hand, we have the most common perspective:

“From my experience in day care centres and nursing homes, there’s a big problem because assistants don’t know a thing about the people they have there.” (Psychologist 1)

Conversely, several nursing homes specialized in Alzheimer’s provide to their staff archives about their patients containing personal information, their genealogy, or what are their interests. Nevertheless, they also stated that these archives are difficult to maintain, requiring too much time to update.

Psychologist 2 alerted to the potential interest of having the nursing homes communicating with the family of their patients. This could bring people together, making it harder to forget that “they still have someone they love in that institution, someone who needs and deserves some attention”. However, the most common approach for the nursing homes is low profile, only providing information when the families inquire them.

Typically, information exchange between staff and family members, is based on telephone calls which are likely to lead to information evanescence. The usage of mailing lists and a Facebook group of discussion was also reported by one of the participants (Psychologist 4).

The collection of materials (e.g., photos) next to the family showed to be problematic. When the patient is still capable of providing the photos to the professional, everything works better. After that, when their cognitive skills are deteriorated, that task is delegated to those who provide care and everything turns out to be a complicated process, filled with idiosyncrasies:

“People fear that I may lose their photos” “If we are requesting many things, that may result in overload: one more thing to search for, one more thing they must do, one more worry.” (Psychologist 2)

4 Designing for Personalized Cognitive Stimulation

With this understanding of current practices, needs, expectations, and possible barriers for adoption, we defined the following goals for a platform to perform reminiscence and cognitive stimulation activities in a clinical setting:

1. Enable agile collection of personal information;
2. Provide continuous awareness and management of personalized therapy;
3. Personalize cognitive stimulation activities;
4. Support group therapy;
5. Engage and involve informal caregivers, namely family and friends.

To accomplish our goals and evaluate its applicability, we developed Scrapbook. Scrapbook is a web application that supports psychologists by allowing them to perform reminiscence therapy and cognitive stimulation activities (individually or in group) with people with dementia, and to keep records of sessions over time. The system uses generic, biographical and personalized materials (pictures, videos, music, and texts with life stories). These materials are collected in an agile way through a set of keywords representative of the patients’ life, and through a mobile application that allows communication and information sharing between informal caregivers, namely family and friends, and psychologists.

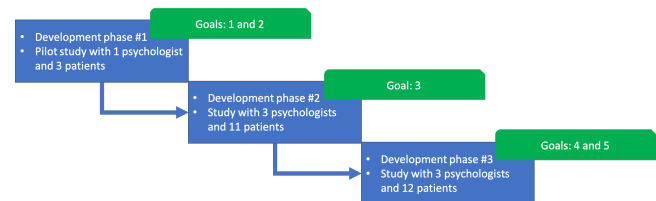


Figure 2. Timeline of study procedure.

4.1 Methodological Approach

Scrapbook was developed using an iterative user-centred design methodology. There were in total three development phases (Figure 2) each one resulting in an evaluation in a clinical setting and in a refinement of the platform. Requirements of the first development phase came from the formative studies presented above.

Our goal was never to measure patient outcomes but rather to understand acceptance, benefits, limitations, and tensions in using and collecting biographical data. Our research protocol was submitted and approved by the *Campus Neurologico Senior* ethics committee. A written informed consent was signed by all psychologists and patients (or responsible caregivers) involved in the study. All collected data was encrypted in our database and psychologists were the only ones who could access it through the platform.

4.2 Study procedure

Our platform was used in two different institutions, a rehabilitation clinic and a care home, by three psychologists and one assistant. We started by conducting a pilot study with one psychologist. Then two more psychologists, from a different institution, participated in the second phase of the study, and in our last phase, an assistant joined the previous group. Before the beginning of the study we performed an individual semi-structured interview with participants (clinical staff) to understand their current practices, needs, concerns, and expected outcomes. Our procedure consisted in meeting with psychologists before each phase of the study to demonstrate the usage of the system, and in the end of each phase where another semi-structured interview was conducted to collect their feedback.

The first phase of the study lasted two weeks. The psychologist had to perform sessions (at least one) with at least three people with dementia. During this period, seven sessions were performed with three patients. Three anamnesis [16] sessions to register patients and four reminiscence therapy sessions. Our second phase of the study lasted two (two psychologists and one assistant) to four (one psychologist) months. During this phase, each psychologist had to register and perform at least four sessions with three patients. No other usage limits were imposed. The schedule of the sessions and its organization were responsibility of psychologists. To enable patients to physically interact with the system, we provided one tablet to one of the psychologists. In total, eleven patients participated in this phase, performing a total of forty-six sessions with Scrapbook. Our final phase had a duration of four months. There were no time nor usage obligatory requirements for the digital tool. Its usage was treated as an applicability indicator. In this last phase, twelve patients had in total thirty-one individual sessions with the platform. Five group sessions with multiple patients were also performed.

4.3 Prototype

In this section, we detail the three phases of our prototype, Scrapbook.

4.3.1 Phase 1: Agile Reminiscence Therapy

Initially our work was focused on reminiscence therapy [1]. Our main goal was to understand if only some keywords could be enough to generate quality material to perform reminiscence therapy and how psychologists and patients adapt and benefit of digitally-supported therapy sessions. Additionally, we wanted to understand how psychologists interact with the platform and to assess the user experience.

Our first prototype was co-designed with one psychologist who defined some clear rules that we should follow:

- User interface must be clean and cannot contain any element that may distract patients from the therapy;

- All materials used in sessions must be pre-validated by the psychologist to avoid unwanted reactions by patients;
- Patient data must be protected and only psychologists should access it;
- The platform should not be time-consuming. Registering a patient and starting a new session needs to be an agile process;

With these in mind, we decided to build a prototype with a simple workflow. Starting a reminiscence therapy session with a patient mandates:

1. Registering the patient;
2. Selecting, from generated materials, the materials to use in the reminiscence therapy;
3. Performing the reminiscence therapy session.

Patient registration. Adding patients to the system is a key process. Ideally, this process should be done with the help of a caregiver. At this stage, we recovered three types of information: personal characteristics of the individual (name, gender, birthday), biographical materials (pictures and videos) and a set of keywords, representative of patient's life, used as seed to obtain personalized materials. These keywords were divided in interests (Music, Movies, Sports, Personalities) and relevant places (such as birthplace or relevant travels). Biographical materials could be inserted as simple images or videos (with an associated description, date and venue), or contextualized as belonging to a life event (such as marriage) or to a relative.

Creating a session. After the registration of a patient our system collects a predefined number of pictures and videos, from Flickr API and YouTube API, associated with the input keywords. Together with the biographical materials, these personalized materials become available to the psychologists, to be used in sessions. Before each session, the psychologists may select the materials to use and the order in which they will be presented. To not overload them with materials there are filters that allow managing the materials being presented. All sessions are recorded and can be later repeated. Session recording also allows psychologists to create the sessions before meeting with patients.

Reminiscence therapy. Reminiscence therapy was presented as a slideshow of pictures and videos, representing subjects to be discussed between psychologist and patient. For each slideshow item, the psychologists can provide feedback (for instance based on the person's reaction), or input personal notes. To perform the therapy the psychologists may use two screens. A first screen allows them to control the session and to take notes, and a second screen, with a clean interface, presents the materials to the patients.

Clinical follow-up. One of the expectations of psychologists is to have something that allows them to record the plan and results of the sessions. Our system records every interaction during sessions (e.g., session length, materials used, feedback). This allows us to create a graphical and detailed visualization of the session evolution over time, which is accessible through the patients' profile pages. This page also allows psychologists to manage information and materials of patients.

Continuous growth of meaningful available materials. Providing feedback about materials is one way to ensure the growth of meaningful available materials. When the feedback is positive, new pictures and videos about the same subjects are recovered from Flickr API and YouTube API, refining the relevant contents about the person.

4.3.2 Phase 2: Personalized Cognitive Stimulation

The second prototype increased the type and number of activities available. Besides reminiscence therapy, cognitive stimulation activities were made available, but still maintaining the biographical stance.

The most relevant changes to this version of the prototype, upon feedback from the study participant were:

- Implementation of three cognitive stimulation activities using personalized and biographical materials: 1) a jigsaw puzzle, where a picture is divided into several pieces and the patients must drag these pieces to the correct positions; 2) the memory flashcards, where several pictures are turned upside down, and patients must flip the pictures one by one until they find all the pairs; 2) and street view navigation, where patients can navigate through the main venues (obtained from Foursquare API) of each one of their relevant places.
- Fearing that web browsers tabs and bookmarks bar may distract the patients, the psychologists requested that all activities are presented in fullscreen;
- Allow the psychologists to hide videos during reminiscence therapy. This way, videos or music keep playing in the background, and the psychologists have the opportunity to ask different questions about that material;
- Redesign of the reminiscence therapy page to run only in one screen. Mostly because of the lack of devices they have and the complexity of all the process of connecting two devices, psychologists did not react well to the idea of using two screens during sessions. Additionally, this new version of the system allowed psychologists to hide distracting elements of screen while a material was being presented;
- Allow psychologists to share patient access with each other, i.e. with psychologists working in the same institution.

4.3.3 Phase 3: Group therapy and Family Engagement

The third version of Scrapbook represented a paradigm shift. If in the first iteration we were focused in supporting exclusively reminiscence therapy sessions, we understood that reminiscence therapy should be seen as another activity that psychologists could perform with patients from a bigger set of cognitive stimulation activities.

Additionally, we wanted to understand if a close collaboration of caregivers could increase the number of biographical materials and consequently increase the quality of sessions. Additionally, we wanted to explore ways to improve the closeness between patients living in care homes and their relatives.

Mixed with psychologists' desire in having new cognitive stimulation activities, we wanted to explore if stimulation games like quizzes could be used to discover more interests and therefore help to build a more realistic profile and scrapbook. Finally, as care homes usually have group therapy sessions we wanted to explore how these sessions could benefit from a digitally-supported cognitive stimulation apparatus.

Patient registration. As the presence of caregivers in the patients' registration process was not usual, psychologists struggled to discover patients background and interests. In the current version of Scrapbook interests are divided into Music, Cinema, Literature, Politics, Sport, Dishes and Hobbies. Interests from each one of these topics (such as musicians, movies, books or sports teams) are previously collected from web APIs and stored in our database. Our system is now capable of providing autocomplete options for each input and to provide suggestions of interests. These suggestions could be based in more generic interests (e.g., if the patient likes Rock music we suggest popular Rock bands), or based in patient's life places (e.g., if the patient lived 20 years in Lisbon we suggest Lisbon historic football teams or traditional dishes). Finally, due to the request of one psychologist, we allow the insertion of pictures and videos just by inserting their URL.

Session organization. If in the first phase a session was exclusively a reminiscence therapy activity, now a session represents a set of activities. Psychologists may navigate from one activity to another always inside the same session. In the end, they may take a note about the session as a whole. All relevant data regarding activities are recorded, allowing sessions to be reviewed as a timeline. A button always present in the top corner allows them to add at any time new information to the profile of a patient. When creating a session, psychologists may now select multiple patients and perform a group session. Through a simple interests matching algorithm, our system suggests materials about common

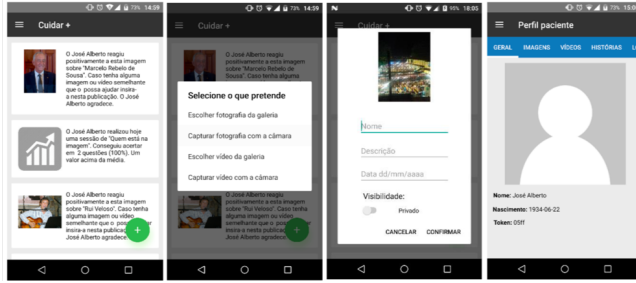


Figure 3. Mobile application. From left to right: Homepage with posts send by psychologists; Submitting materials; Add description to the material to be submitted; Profile of a patient

interests among patients. Additionally, if not satisfied with a specific personalized material, they may now replace it with another material about the same subject.

Cognitive stimulation activities. Eight new activities were introduced in this phase: 1) Sort, where patients should sort a timeline of life events or relatives' birthdate; 2) Touch, where random pictures fly from the left to the right of the screen and patients should touch a specific picture (for example touch a picture of a specific relative when displayed); 3) Speak, where pictures are displayed and patients should say the name of who or what is in the picture and the system automatically analyzes the answer through the microphone (in some levels the partial or the full name may also be presented), and, 4) quizzes. There are five different quizzes. Questions are always related with the patients' origins (country and city) and, when they have a sufficiently rich profile, according to their background and preferences. More generic quizzes ask to the patients who or what is in a picture being presented or, alternatively, to discover through clues and a distorted picture who that person is. Additionally, there are more subject-oriented quizzes about music (such as guess the music or guess the artist), sports (such as guess the athlete in the picture or guess the stadium of a football team) and politics (e.g., guess who was the successor of a specific president). When applicable, activities have an adjustable difficulty level. For flashcards, a higher level means less time to see the pictures to flip, for puzzle it means more pieces, for quizzes means harder questions. An algorithm developed by us, assigns a level of relevance to each interest or place stored in our database. When a patient performs a quiz of level 1 (very easy), only questions about very relevant interests or places will be made. Quiz questions and answers are automatically generated from stored data.

Involving caregivers. Caregivers and psychologists can access and manage patients' profile through an Android application (Figure 3). The main goal of this application is to

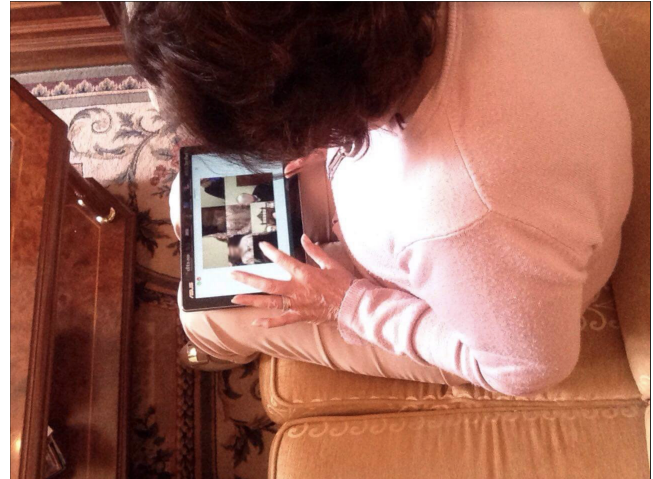


Figure 4. Patient performing a jigsaw puzzle.

allow caregivers to contribute with information and materials to the profile of a specific patient [13]. Texts representing patients' life stories may also be inserted. Psychologists have the final decision over materials, and are notified each time something new is added to a profile. Psychologists are responsible for adding caregivers. After adding a caregiver (providing a name and email address) to the profile of a patient, an email, with a token to be associated with that patient, is automatically sent to that caregiver.

To engage caregivers, we created a post system. After each session, Scrapbook generates a list of posts that psychologists may send to caregivers, which may be just to inform that the patient performed a specific session or activity (may include performance details) or to ask for more materials about subjects with positive feedback. Additionally, this application also allows the exchange of messages between psychologists and caregivers. Psychologists who do not feel comfortable with this functionality may turn it off.

5 Results and Discussion

Throughout this section we report the results of our study, while discussing the evolution of the most relevant subjects of our work. From now on, psychologists will be referred as P1, P2 and P3. Results are derived from interviews with psychologists, and usage logs. We encrypted all personal data and had no access to the information, photos, or other materials that psychologists or family had added to the platform. However, we did collect usage data: number of elements added, number and duration of sessions, time spent with each media element, type of activities performed, among other.

Acceptance of the platform. Overall, Scrapbook was well accepted by all stakeholders. As the organization of the

sessions were responsibility of psychologists, some have chosen to perform sessions exclusively with our tool and others decided to use it as a complementary tool and mixed its use with more traditional methods. Scrapbook was perceived as another tool they may use to perform their work. No negative impacts were reported regarding the introduction of Scrapbook in the clinical process.

In our first phase, the platform had a positive impact in two of the patients, who enjoyed being exposed to the platform and saw the introduction of the platform as something very natural. For them, it was an opportunity to discuss about subjects that they would usually not talk about. P1 referred that with the use of the platform and the increase in the number of biographical and personalized contents, there were more materials to work individually. She reported that one of the patients *“never attended school and for her this is learning... she loves learning... it is like she is going to school even though we are working here”*. The closeness created between one of the patients and P1 was also referred as a positive outcome. Unfortunately, the third patient was in an advanced stage of the disease and was not aware of the paradigm shift of sessions.

In the following phases of the study we provided a tablet to P1. After some training, patients were able to physically interact with a touch screen, which generated excitement (Figure 4). There were also reports of patients who were able to use a mouse. When not possible, psychologists were responsible for interacting with the mouse following patients' instructions. Mainly due to the lack of clinical staff, some care homes end up performing group sessions with patients; therefore, we introduced the group therapy functionality in our last study. Unfortunately, it ended up not being explored. The platform was indeed used for group therapy but by resorting to the creation of a general (fake) profile for the group, instead of the group feature. Once these patients were only present in group sessions, there was no benefits of adding them individually. The small screen of the tablet was also seen as a limitation for the group sessions.

One interesting report of P1 and P2 was that some patients may not see this tool as a professional tool that may help them. When performing activities or asking very basic questions they may feel underestimated. One of the psychologists referred that she tried to explain, before each activity, the brain functions that will be stimulated. Other said that, *“once patients are paying to perform the session, it is important to them to know that they are not just playing a game”*.

Perceived effectiveness of Scrapbook. Our procedure in the first phase affected positively one patient whom was previously unable to formulate a sentence. During the study, he was able to sing the refrain of several songs. P1 referred that: *“here I put the music he likes, that he really likes and he did something that I was amazed at. For him, have a fluency of speech is very difficult and he sang with me almost*

the whole refrain, which I had never seen”. P1 was aware that this patient enjoyed listening to music, but once the engagement with Scrapbook was higher, P1 was able to explore his likings. Positive effects on the levels of attention, apathy and ambulation were also reported in this phase. In following phases, P2 and P3 highlighted improvements in the level of well-being and mood. P3, who usually used our tool only in part of the sessions, stated that she prefers to use Scrapbook in the last part of sessions so that patients can leave with a better mood and better feeling of well-being.

Activity feedback. In our first phase, the focus was reminiscence therapy, and, as mentioned above, this therapy had a positive impact in patients. In the second phase, and following psychologist's feedback, we decided to use the available materials to also perform cognitive stimulation activities. These new activities have raised some problems. Each patient has unique characteristics and may be facing different disease stages. One negative aspect reported by P3 was that the flashcard activity was not adapted to patients characteristics, and sometimes pictures flipped to fast. Even with only two pairs of pictures, some patients could not complete this activity. Additionally, there seems to be a disparity between activities performed with biographical materials and activities performed with personalized materials. Psychologists refer that patient engagement was higher when activities, particularly the puzzle, were performed with biographical materials. Puzzles got positive feedback by psychologists, who referred they already tried to perform puzzles with patients before but that with biographical materials their engagement was higher, even in more advanced stages. Overall, they expressed a desire to have more cognitive stimulation activities.

In the last phase, we introduced difficulty levels in activities and more cognitive stimulation activities (mainly quizzes). However, not every patient adapted well to all activities. The complexity of the activities or the refusal to use new technologies are the biggest barriers. As in this version we had a bigger number of activities, all patients adapted well to at least two of them (depending of their likings, interests or cognitive skills). According to the usage statistics, puzzles and reminiscence therapy continued to be the favourite activities. The quiz where people had to discover who was in the picture was performed almost by all patients. More specific quizzes about music, sports or politics were applied according to people's preferences. However, P1 complained about the small amount of available questions in some quizzes, which lead to some frustration of patients (the low number of available data about Portugal in Web APIs restricted the amount of questions we could generate).

Quality, diversity and quantity of available materials. One of our main concerns was the quality and quantity of the available materials. If with biographical materials we

only had to focus in how to get them, with personalized materials we wanted to ensure their usefulness. In our first phase, P1 mentioned having at least one good image about each subject she wanted to discuss about; however, the quality of pictures collected from Flickr API was not the best. For the second phase, we tried to improve the quality of images by adding filters to Flickr search queries. This change was not enough. The psychologists complained about the quality and diversity of personalized materials. P3 referred that these contents were enough to perform one or two sessions but then they started to be very repetitive. This may also be related with the fact that two of the psychologists did not met with caregivers to register the patients and ended up performing the therapies only with information provided by the patients (according to them, mostly not enough). To suppress these problems, we reorganized the way we get personalized materials. Pictures of interests are now collected from Wikipedia and last.fm, and pictures of places from Foursquare. A functionality to replace pictures or videos was also introduced in this phase. Overall, the quality improved and the patients “*reacted very well to the presented materials, according to their interests*”. To watch some photographs lead to “*enthusiastic and surprising reactions*” from several patients.

Other factors with influence in the quality of personalized materials were the small size of some pictures and captions presented in pictures and videos. For example, the display of the title of YouTube videos allowed patients to previously find what the video was about.

Uploading pictures to patient’s profile was initially pointed as another limitation. The psychologists usually took the pictures with their mobile phone, uploading them to their laptop and then to Scrapbook website. Despite they could have uploaded the pictures with their mobile phone (through the web browser), they felt that a mobile application could help them. We introduced the mobile application, in the third phase, to help psychologists and caregivers to upload biographical materials but ended up not being used as expected.

Increased knowledge about patients. Psychologists reported three main factors as being decisive for an increase of knowledge about patients: anamnesis sessions, caregiver involvement, and performing activities with Scrapbook. In the first phase, anamnesis sessions with patients and their relatives, that without Scrapbook would not have happened so early, allowed the psychologist to better know the patients. For one patient, she reported that now she sees a “*completely different person*”. The presence of the caregivers in these sessions and the information sharing between psychologist and caregivers (mainly by email) also had a positive influence. However, some caregivers do not have availability to be present in the registration process. Many care homes apply an admission form when patients first come in, and some psychologists, in the second phase, used the

information collected in the admission as a starting point to their interventions. Once the information about patients was not enough, psychologists tried to explore random interests (such as famous musicians) and see how people reacted. To help psychologists to discover patients’ interests, we introduced in the last phase the quiz activities and the mobile application. One of the goals of these activities was to allow psychologists and patients to discuss about general knowledge questions, and therefore discover patients’ likings. According to P1, performing these activities allowed an intuitive sharing of interests between psychologist and patients, which were not previously known. Additionally, P1 highlighted patients’ involvement in the Street View and Reminiscence Therapy activities, which stimulated them to tell stories about relevant places.

Caregiver involvement. Involving caregivers in the process was one of our initial goals and can be analysed by two perspectives. On one hand, information sharing between psychologist and caregivers increased, and caregivers contributed with material (mainly photographs) to be used in sessions. Some of them were physically present in registration sessions and others sent photographs by email. Additionally, they felt positive about the usage of Scrapbook (“*All things that may help are welcome*”). On the other hand, our approach failed in involving continuously caregivers in the process. Our initial idea was to use a social network to interact with friends or relatives, and to create posts asking them to provide materials or to deliver feedback about sessions. This idea raised some questions mainly about privacy or the low technological skills of relatives. As a first step, we decided to create our own mobile application, which ended up not being used as expected. In total, only two caregivers used the mobile application and contributed with data (low technological skills of elders in Portugal was noted as a possible reason). However, P1 said that caregivers felt that they had an important role in the therapy. She also referred that the process of inviting caregivers (through an email) is very simple, and found excellent to be, in the future, able to send posts to caregivers with feedback about the sessions.

6 Conclusions

Performing therapy with people with dementia benefits from knowing their background and interests. We found that psychologists were poorly supported both in gathering and storing knowledge about a person, as well as in maintaining awareness of how people respond to this identity and memories over time. Through a longitudinal deployment of a digital platform, we found preliminary evidence that psychologists welcome the usage of digital tools in a therapy context. Personalized activities have benefits both in terms of patient reactions and engagement, as in the knowledge and awareness it provides to psychologists about the person they

have at their care. Family participants felt engaged with therapy and contributed with materials. However, there was an overall underwhelming usage of the platform which suggests that it still carries an overload and an informal connotation that is not aligned with people's expectations of (cognitive stimulation) therapy. Future work should be dedicated to further explore how to align the tools with therapy practices, and even more so, with patient and family expectations.

Acknowledgments

This work was supported by FCT, I.P., through funding of project mIDR (AAC 02/SAICT/- 2017, project 30347, co-funded by COMPETE/FEDER/FNR), and of the LASIGE Research Unit (UID/CEC/00408/2013). We would like to thank Campus Neurologico Senior, LATI, and Alzheimer Portugal for their collaboration in our studies, and all participants.

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