

Communication Support System Between Persons with Dementia and Family Caregivers using Memories

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Abstract—Persons with dementia have lost important memories, and their caregivers are exhausted by caring for them, especially family caregivers. We aim to support persons with dementia recall memory by talking about their memories together, place them in their life history, and communicate with their caregivers. The proposed system uses photographs as triggers for memory recollection. The demonstration verified that recollection support of memory using photographs is promising as triggers for conversation and organization of memory, while further revisions are required.

Keywords—Persons with dementia; caregivers; recall; photograph; memory; communication.

I. INTRODUCTION

Recently, Japan has progressed into an aging society, resulting in an increase of persons with dementia [1] [2]. Although the symptoms of dementia change depending on the type of disease, the main symptoms can be divided into core symptoms and BPSD (Behavioral and Psychological Symptoms of Dementia). The core symptoms are the decline of aspects of intelligence function, such as defects of memory and impaired orientation. BPSD include wandering and hallucinations, which become a heavy burden for care workers. For the family members and other relatives it seems that persons with dementia cannot understand anything. A decline in emotional function, however, does not always accompany the decline in intelligence function. Therefore, sufficient consideration is needed when caring for dementia patients. In Japan, family caregivers often support persons with dementia in addition to using day-care facilities, but their circumstances are deeply stressful, because they often do not have sufficient knowledge of dementia and so give care to them by trial and error, and they cannot take their eyes off their patient. It is also often hard to obtain cooperation with surrounding communities, due to the negative image of dementia and low social recognition.

In this study, we aim to support the recall of memories of a patient and his or her family, the most familiar presence for persons with dementia. Family caregivers talk together about their memory. This is not an act of the caregiver taking care of the patient alone, but one which

creates a good environment in order to help each other. Also, if neither the person with dementia nor the family can recall the memories, we provide a trigger for recollection by presenting social events and information similar to the lost memory. As a result, persons with dementia can recall memories about their family, and family caregivers are able to actively communicate with other members including the person with dementia.

A brief outline of this paper follows. In chapter 2, we describe the significance and role of memory, which is lost by dementia. Chapter 3 describes research trends of persons with dementia and caregivers. Chapter 4 and 5 describe system proposal and system functions, which is based on the consideration in chapter 3. Finally, chapter 6 describes evaluation of the system.

II. FUNCTION OF MEMORY

This section describes the significance and role of memory, which is lost by dementia.

Memories are our own private episodes, formed from an individual person's experiences in the past. Even if people experienced the same episode, how they feel about it may differ from person to person [3]. Moreover, our present "egos" has been formed by the accumulation of our own episodes. Memories are fully private unless we talk to someone about them. Thus, memory has the role of reminding us of our consciousness of self.

Viewed from another side, people talk about their memories to prompt mutual understanding. Talking together on the pasts means exchanging a part of their egos. As a result, people are able to prompt mutual understanding. Therefore, memory has a role of building and maintaining human relationships.

However, people forget memories as time goes on. People find it hard to recall memories which they have not recalled for a long time, and thus triggers are required to recall them. Examples of triggers include seeing a photograph, reading a diary, talking with family and friends, hearing a long-forgotten tune, and smelling an old familiar perfume. In particular, photographs hold a variety of types of information. They are associated with a specific annotation, such as date and time, place, and events. A photograph helps people indulge in reminiscence

alone and share their memories with others, led by various annotations involved in it.

A. Memory Communication

Memory has two roles: first one is to remind us of our past experiences, and second is to build and maintain human relationships, as stated above. In addition, having a conversation with others promotes memory sharing and increasing our memories. Normal actions such as talking with family and friends are communication carried out unconsciously; but can be characterized as memory exchanging or 'Memory Communication' [4].

Memory Communication requires the following three elements.

- a) The communication methods and partner(s).
- b) The memory and a related episode.
- c) Something that acts as the trigger to recall the memory.

Many elderly persons talk with family and friends on a regular basis. Talking about memories is an effective way to communicate with a stranger in nursing care homes or hospitals. Communication methods are to meet and talk in person, and bring photographs. Further, recently cell phones and the Internet have been developed, allowing people to communicate with others even if they are far away. It can be predicted that triggers will be different for each elderly person, but looking at photographs of past eras and listening to old popular songs certainly promote remembering.

We have described the significance and role of memory in this section. Memory belongs to each individual person and is an important element for expressing one's personality. However, persons with dementia gradually lose their memory, thus losing proof of their existences.

III. RESEARCH TRENDS

A. Support Systems for Persons with Dementia

Recently, widespread use of cell phones and the Internet is progressing. As a result, support systems which utilize such equipment have been rapidly increasing, such as, a movement navigation system using photographs [5], and a remote interactive support system [6].

- a) Movement navigation system using photographs.

Traditional map-based movement support systems are not effective for persons with dementia because it is difficult for them to learn the route and recognize landmarks. Consider this problem and developed a system which encourages understanding of the route by using photographs and animations on a cell phone. It shows a direction to turn at a junction and indicates important signs which show the correct route to a destination, as shown in Fig.1.

- b) Remote interactive support system.

This system uses a videophone, and is able to show photographs and videos about memorable episodes even from a distance (Fig.2). Persons with dementia and their

caregivers can reminisce and share memories at home, looking at the same photos and videos, without going to a public institution. As a result, persons with dementia can obtain some stabilization of their mental state, and this system can reduce the burden on the caregiver.

B. Organization Support for Caregivers

There have been only a few attempts to support in-home care. Examples of support services for caregivers include the use of nursing home care and care helpers. However, these services cannot sufficiently reduce the burdens on family caregivers, because the use of nursing home care is expensive and the utility time is limited.

Under this situation, there have been some movements in which caregivers have taken the initiative to confront the difficulties of care. For example, the Male Caregiver Network is an organization of which the members comprise of male caregivers [7]. The activities of the organization include holding exchange parties and lectures for male caregivers. Many of the participants include both veteran caregivers and beginners. These events are a great reassurance to beginners because they can consult with caregivers in similar circumstances. Conversely, veteran caregivers can reflect on their care history through communication with the participants. The members can generate motivation to continue care. In this way, the organization aims to provide a place to talk about and share the worries of care between caregivers.

C. Consideration

Researches which use information technology to support persons with dementia share the aim to enable them to live an independent life. If they can lead as independent a life as possible in their home, this will reduce the burden of caregivers. Most researches do not aim to target caregivers directly.

However, providing support for caregivers, not only for persons with dementia, is necessary because if persons with dementia live in their own homes, they need help from their family caregivers. They need plenty of nursing care time, and as a result, the burden on caregivers increases and they become exhausted. An environment which supports the caregiver and listens to their troubles is required. Caregivers are taking initiatives themselves such as in the 'Caregivers Male Network', but not every caregiver can participate in these activities. Furthermore, previous research focuses on only negative aspects of home care [8]. The burden of care of persons with dementia has been found to be greater than care of persons without dementia. However, recent studies have identified a need to approach the positive aspects of home care [9]. Although caring for family members is recognized as a road which everyone must eventually take, on the other hand, it is difficult to continue due to the heavy burden. Therefore it is necessary to develop a support system for in-home care as part of the social system.



Figure 1. Movement navigation system.

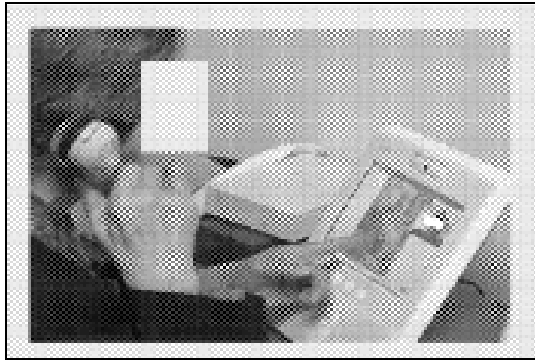


Figure 2. Remote interactive support system.

IV. SYSTEM PROPOSAL

A. System Summary

In this study, photographs are used as a trigger to recall memory. People can extract rich information from photographs because they have variety of visual cues about their contents. People have a tendency to promote their bonding by confirming the shared experiences and photographs provide an opportunity to start a conversation about shared memories of the family. Furthermore, most families have kept photographs in the family album for many generations.

Rich information of photographs can be classified as follows:

- a) Date and time, location when the photo was taken.
- b) Reason why the photo was taken at that place
- c) Relationships with person(s) in the photo.
- d) Feelings about the scenery and objects in the photo.

Thus, the information obtained from one single photograph can be abundant. In this system, we register the event, location, and date and time as information about each photograph. As many photographs simply show daily life spent with family, these photographs are useful for recalling memories of happy past days and promoting bonding of family through communication of shared happiness.

B. Proposed Method

Users (persons with dementia, family, and family caregivers) register annotation of each photograph - event, location, and date - as a set into the photo information database. Then, when a photograph is selected, the system displays the event, the location, and the day, in that order. This is because the event, which we place first, is considered as an experienced and repeated memory. Experienced and repeated memory is comparatively well retained.

However, it is difficult for persons with dementia to recall a detailed memory just by looking the registered information of the photograph. Furthermore, the family caregiver may not always remember the event shown in the photograph. Therefore, as information to aid memory recollection, the system shows another photograph registered with similar information or associated social events. The content in the social events database stores effective information for recollection, such as social events which occurred during the same period or information associated with the dementia patient's hobby.

In addition, by registering and displaying the life story of the person with dementia that are recalled, they are able to look back on their own history and place each episode in order on the timeline.

The following steps indicate how to use the system and Fig. 3 shows a graphical representation of the system process.

- a) Register the photograph information: the location, the date, and the event.
- b) Show the information of the selected photograph. If only using registration information is not enough to trigger recollection, show another photograph with similar information.
- c) If both the dementia patient and the family caregiver do not remember the photograph, and effective content which is judged to help recollection exists in the social events database, the system refers to the social events database.
- d) Show the result of the inquiry.
- e) The family members share the recalled memories through conversation about the period, the location, or the event of the photograph. Then, if a new memory is recalled, the content is added to the photograph database.

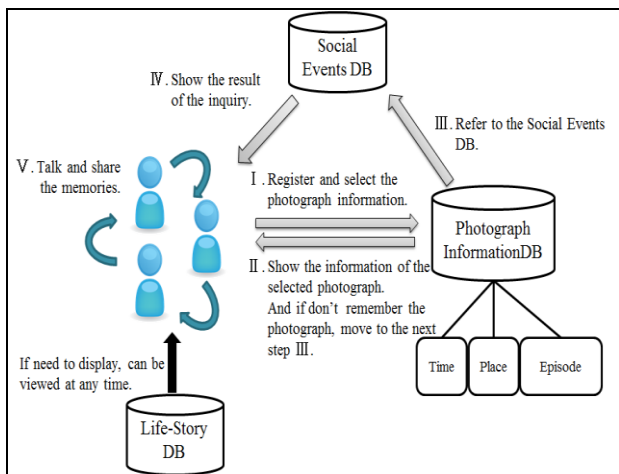


Figure 3. Graphical representation of the system process.

V. SYSTEM FUNCTIONS

A. Registration Function

Using the registration function, the system registers a photograph, the photograph information, social events information, and life story information. Photographs are stored one by one in a special folder, and photograph information, social events information, and life story information are stored in a corresponding database respectively. Fig. 4 shows an example of the photograph information registration screen. The photograph name is set to the photo's date and time of registration to aid smooth use of the system. The reason why the system uses the date and time of registration as the photo name is that it would be difficult for persons with dementia to decide and input names for photos. In addition, the reason why the system registers the photographs one by one is that users are expected to recall some related memories by looking at each photograph.

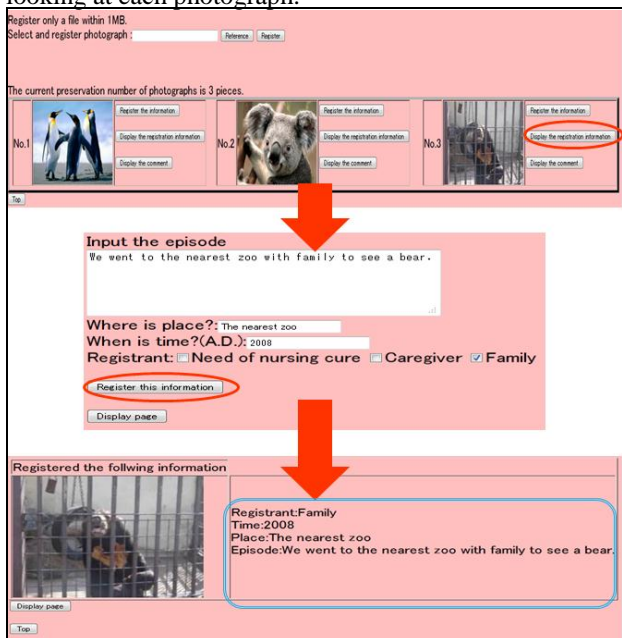


Figure 4. Example of photograph information registration screen.

B. Recollection Support Function

The recollection support function is described below.

- a) Fig. 5 shows another registered photograph taken during the same period and its photograph information.
- b) Fig. 6 shows the social events of a similar time, taken from the social database
- c) Fig. 7 shows the dementia patient's life story.

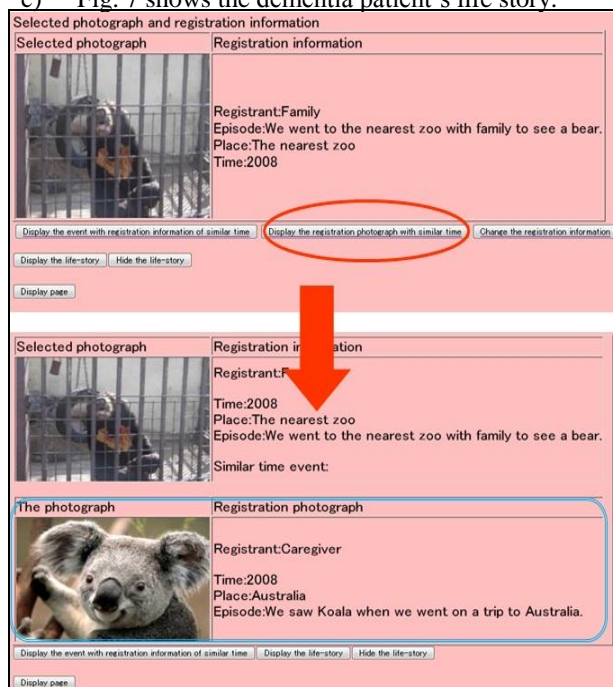


Figure 5. Example of a photograph taken at a similar time

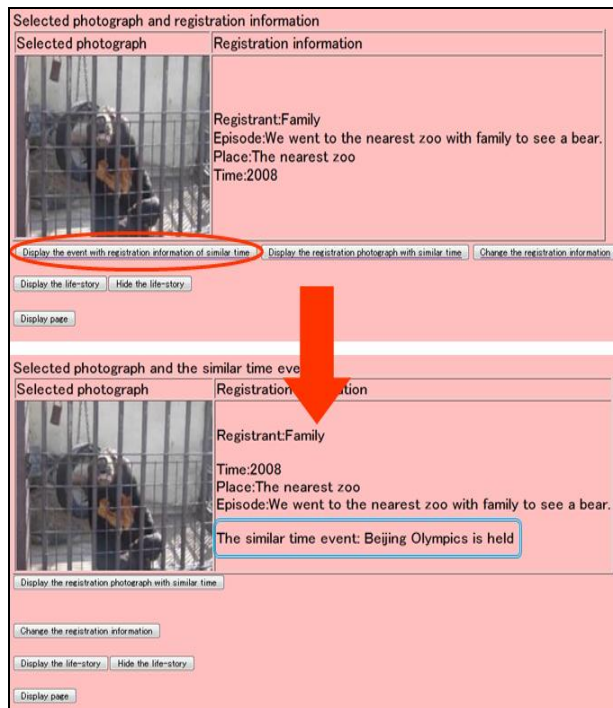


Figure 6. Example of photograph of events of a similar time

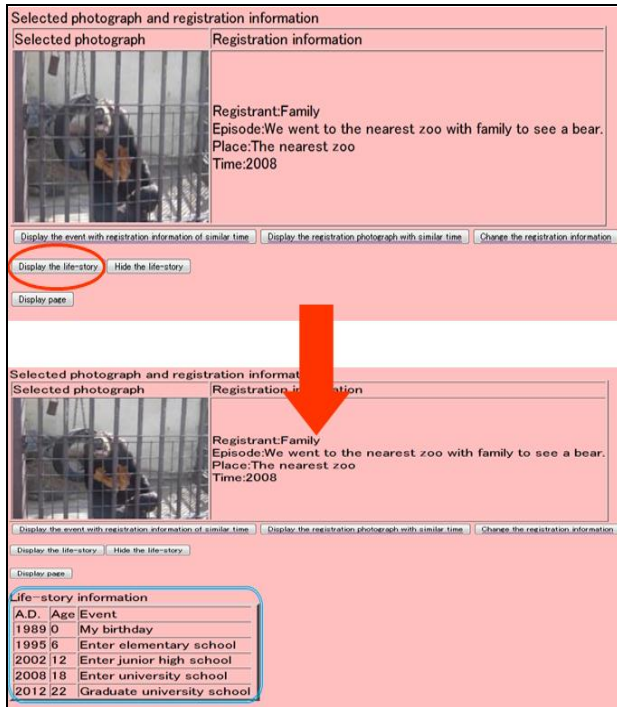


Figure 7. Example of dementia patient's life story

The registered photographs are displayed in chronological order and when a photograph is selected, its information is shown. When the system shows the selected photograph's information, it displays the event, the location, and the date in that order, as stated above. Afterwards, it shows the associated social events, the registered photographs with similar information, and the dementia patient's life story. The reason why the system shows photograph information taken during the same period is that photographs of the same period have some kind of relationship with the selected photograph, and users may recall the memory even if they do not remember the details of the photograph. In this system, "same period" is defined as when the registration year is the same. In addition, the system shows the life story of the person with dementia in order to support recollection. The life story information is not always shown, however. Users can show or hide the life story information optionally. The system supports recollection by using life story, enabling dementia patients to look back on their lives.

VI. EVALUATION

A. Evaluation Summary

An evaluation experiment was conducted with the cooperation of four participants, A and B were family caregivers, C and D were veteran caregivers. The evaluation method was to ask them to use the system and discuss on the information of each registration, then afterwards, to answer a questionnaire on a 4-point scale. In addition to the questionnaire, we asked them to write free comments about the system.

B. Evaluation Results

Table I shows the questionnaire items, and Table II shows the evaluation results. In Table II, 1-point means that it's difficult and there are many works, and 4-point means that it's appropriate.

As is evident from the results in Table II, there was variation in the answers about inputting the information into each database. This was largely dependent on the user's experience level of personal computers. In fact, one of the evaluation participants had never used a personal computer before, and answered that it was hard to input the information into each database. Therefore it is necessary to develop the man-machine interface to improve ease of input for people who have never used a personal computer.

Regarding the efficiency of using memories, we obtained feedback that "memories are useful for supporting elderly persons, because they often talk about old times". In addition to this feedback, another feedback was obtained that the recollection stories might be different depending on the user's gender. For example, in the man's case, he would talk about his acts of heroism and events of the days of working. But in the woman's case, she would talk about child-rearing. Furthermore, the users suggested the opportunities to communicate with persons with dementia during the registration process. However, there was the negative opinion that the system will be difficult for persons with dementia to use, because usefulness of the system will be influenced by their mental state at the time of use. If their state is unbalanced, they will be unable to use the system. Another negative feedback indicated that the system may not be useful for all persons with dementia, because there may be memories that they do not want to recall. Such situations should be considered in using this system for persons with dementia.

Regarding the recollection support function, the opinion was obtained that the system encouraged recollection of memory that preserves the user's uniqueness. The information which is registered in each database depends on the individual. Furthermore, the life story is useful for the recollection of old memories, because it represents one's own history. Talking about old memories and one's life story is effective communication. However, the life story function is still poor in this system. The life story function needs to be improved to efficiently aid memory recollection and sharing.

The responses to Questions 9 and 10 suggest that this system has the ability to aid recollection of memory and better communication with others. If a new memory is recalled, it becomes a common memory, and the users can talk about it and communicate with each other.

TABLE I. QUESTIONNAIRE CONTENT

Q1	Photograph information DB: Can you input smoothly?
Q2	Photograph information DB: Does it take a lot of work to use?
Q3	Social events DB: Can you input smoothly?
Q4	Social events DB: Does it take a lot of work to use?
Q5	Life story information DB: Can you input smoothly?
Q6	Life story information DB: Does it take a lot of work to use?
Q7	Life story: Do you feel the life story is useful for recall?
Q8	Life story: Were you able to visualize or recall that time?
Q9	Effectiveness: Did you recall anything other than the information which was displayed by the system?
Q10	Effectiveness: Could you communicate with your partner well?

TABLE II. EVALUATION RESULTS

	Q 1	Q 2	Q 3	Q 4	Q 5	Q 6	Q 7	Q 8	Q 9	Q 10
A	3	2	3	2	2	2	2	3	3	3
B	1	3	1	3	3	3	2	2	3	4
C	3	2	3	2	3	2	3	2	3	3
D	2	2	2	2	3	2	3	3	3	4

VII. CONCLUSION AND FUTURE WORK

In this study, a support system was proposed to aid memory recollection for persons with dementia and

family caregivers by using photographs and associated information. The system supports the recollection of memory via information about the selected photograph and related social events. Therefore, by talking about these, we aimed to intensify the activation of family communication.

The next step of this study is to improve this system through consulting with persons with dementia.

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