

Communication Support System Between Persons with Dementia and Family based on Memory Recollection and Life Story

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Abstract— Family caregivers who support persons with dementia are deeply stressful because they do not have sufficient knowledge of dementia and give care to them by trial and error. Memory recollection and memory communication are found to be effective for intelligence and emotion of persons with dementia. 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. In this evaluation, it is shown that the life story has a high possibility to promote communication with person with dementia and the family. Thus, we also propose a communication support system which focuses on the life story. This system supports the communication by comparing the life stories of family, and supports the memory recollection of the person with dementia by using “family life story.”

Keywords-Persons with dementia; caregivers; memory recollection; photograph; communication; sharing of life story.

I. INTRODUCTION

Recently, Japan has progressed into an aging society. Figure 1 indicates the population aging rate of 5 countries and shows that Japan has the highest rate of aging population. This situation causes an increase of persons with dementia because an elderly person has high incidence of dementia [2] [3]. Figure 2 shows the incidence rate of person with dementia for each generation in Japan. Over 85 years old, incidence of dementia reaches more than 25.0%, that is, one of four people will develop dementia over 85 years old.

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 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.

The evaluation results show that our system is effective for the memory recollection, and that it promotes the communication with person with dementia and the family caregivers. In the evaluation, it is shown that the life story is a good content for the memory recollection and communication. Thus, we also propose an extended system which focuses on the life story. In this system, by comparing the life stories of all the family, they can talk about them. In addition, based on the registered life stories, the system proposes the expected life story of a person with dementia. By using the proposed life story, the family talks about them with person with dementia, and create true life story by modifying it.

A brief outline of this paper follows. Section II describes the significance and role of memory, which is lost by dementia. Section III describes research trends of persons with dementia and caregivers. Section IV and V describe system proposal and system functions, which is based on the consideration in Section III. Section VI describes evaluation of the system. Finally, Section VII and Section VIII describe development study and future works.

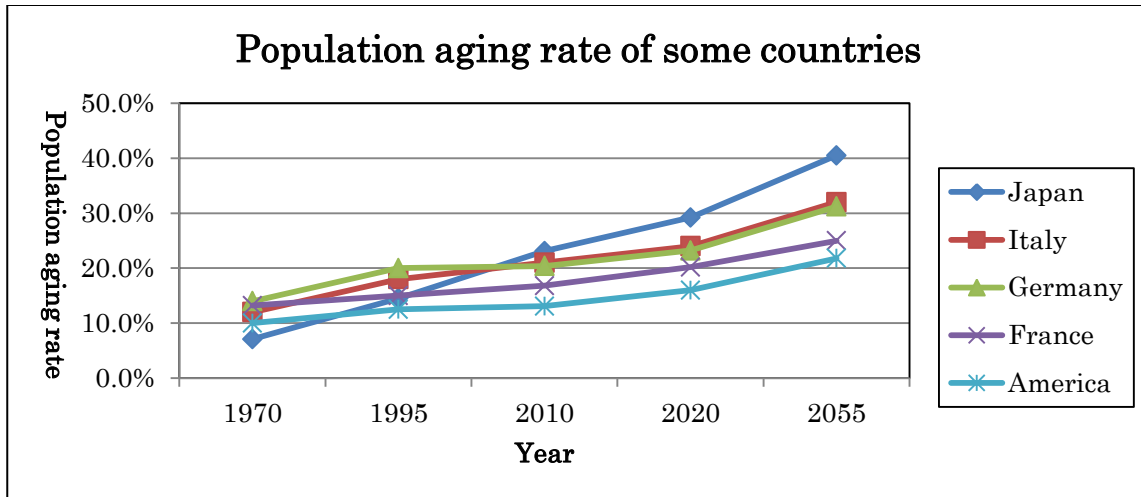


Figure 1. The population aging rate of some countries.

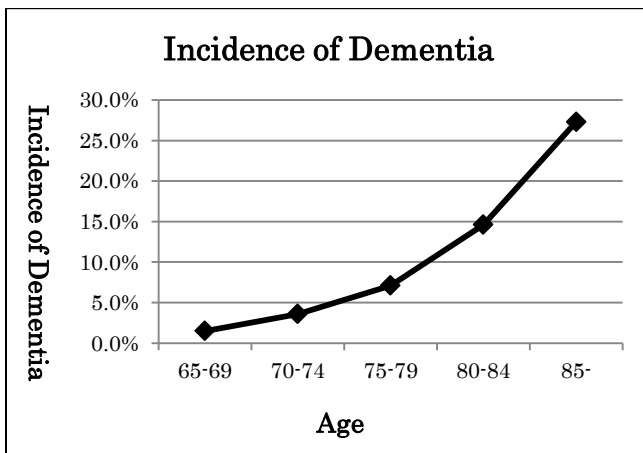


Figure 2. Incidence of Dementia in Japan.

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 [4]. 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 exposing and exchanging a part of their egos. As a result, people are able to prompt mutual understanding. Thus, 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 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' [5].

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.

The significance and role of memory have been described 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 [6], and a remote interactive support system [7].

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 Figure 3.

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 (Figure 4). Persons with dementia and their caregivers can reminisce and share memories at home, looking at the same photographs 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 [8]. 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.



Figure 3. Movement navigation system.

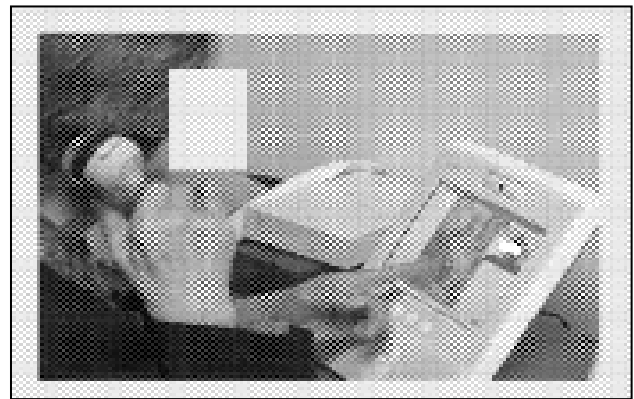


Figure 4. Remote interactive support system.

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 their lives as independent 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 [9]. The burden of care of persons with dementia has been found to be greater than care of persons without dementia. Recent studies have identified a need to approach the positive aspects of home care [10]. 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.

The research trends have been described in this section. Not only focus on persons with dementia, need to consider how support for their caregivers.

IV. SYSTEM PROPOSAL

A. System Summary

The focus of this study is on the recollection of memory of person with dementia. By communicating with person with dementia and his families about their memory, it is expected that the person with dementia recall his memory and, moreover, that the communication between them is activated. Such active communication will lead to reduction of burden of caregivers.

The system aims to support persons with dementia recall memory. Photographs are used as a trigger to recall memory. People can extract rich information from photographs because they contain 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:

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

Thus, the information obtained from one single photograph can be abundant. The system registers 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 photograph information database. 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 the details of 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, the system shows another photograph registered with similar information or

associated social events, as information to aid memory recollection. 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 Figure 5 shows a graphical representation of the system process.

- Users register the annotations of photographs: the location, the date, and the event.
- When a photograph is selected, the system shows the annotation. If the annotations are not enough to trigger recollection, show another photograph with similar annotation.
- 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.
- The system shows the result of the inquiry.
- 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.

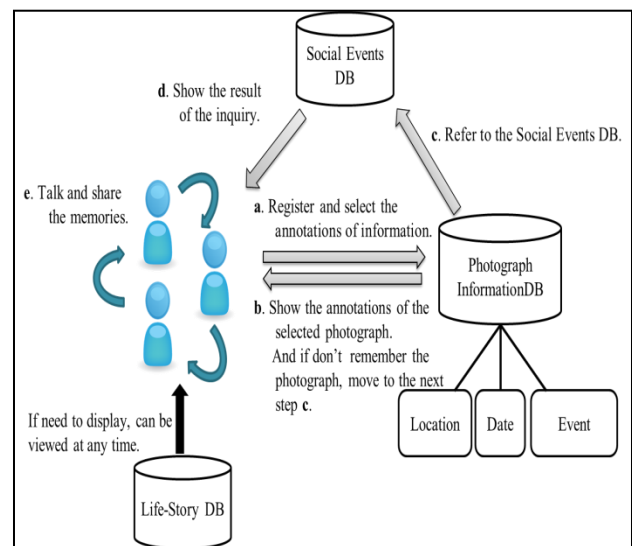


Figure 5. The system process.

V. SYSTEM FUNCTIONS

A. Registration Function

Using the registration function, the system registers a photograph, the photograph annotation, social events information, and life story information. Photographs are stored one by one in a special folder, and photograph annotation, social events information, and life story information are stored in a corresponding database respectively.

a) Registration Function of Photograph Annotation

Figure 6 shows an example of the photograph annotation registration screen. When a registrant presses “Register” button after selecting a photograph, this registration screen is displayed. In this page, the registrant inputs the episode, place, time of the selected photograph. The photograph name is set to the photograph’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 photograph name is that it would be difficult for persons with dementia to decide and input names for photographs. 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.

b) Registration Function of Social Events Information

Figure 7 shows an example of registration screen of the social events information. For an event which the user wants to register, the user inputs the content and year of the event. When the user wants to confirm the registered information, press the “Show all registered information”

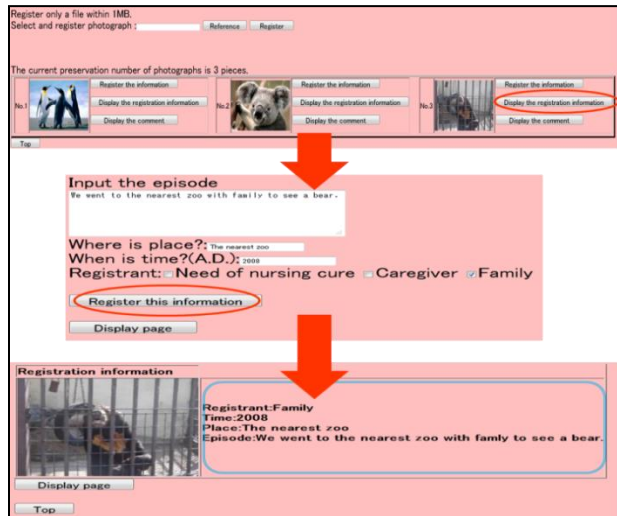


Figure 6. Example of photograph annotation registration screen.

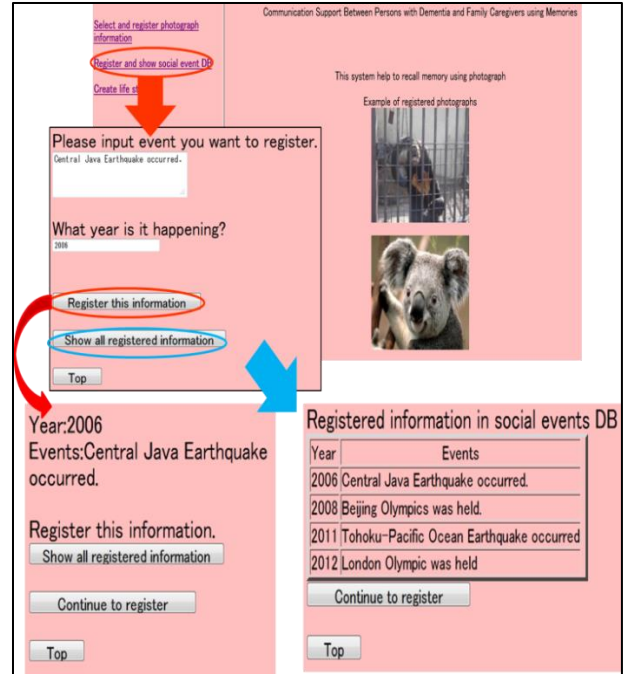


Figure 7. Example of social events information registration screen

button. Then the registered information is displayed in ascending order by years.

c) Registration Function of Life Story Information

Figure 8 shows an example of the life story information registration screen. Input the content of life story, years and age at that time. Like above b), the registered information is displayed in ascending order by years.

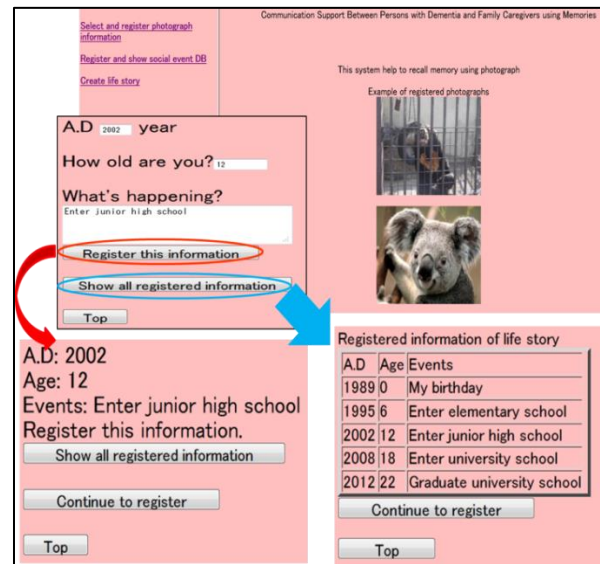


Figure 8. Example of life story information registration screen

B. Recollection Support Function

The registered photographs are displayed in chronological order. When a photograph is selected, its annotation is shown. When the system shows the selected photograph’s annotation, it displays the event, the location, and the date in that order, as stated above.

Afterwards, to support the recollection of the user, the system shows some additional information for the selected photograph. The additional information shown in the system is described below.

- a) Another registered photograph taken during the same period and its photograph annotation (Figure 9),
- b) The social events of a similar time, taken from the social database (Figure 10), and
- c) The dementia patient’s life story (Figure 11).

The reason why the system shows photograph annotation taken during the same period is that photographs of the same period are assumed to 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.

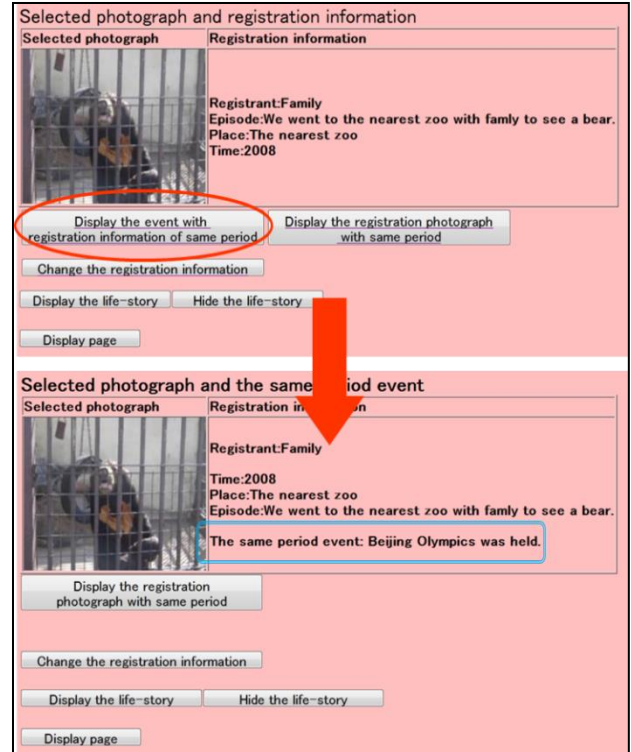


Figure 10. Example of photograph of events of a similar time



Figure 9. Example of a photograph taken at a similar time

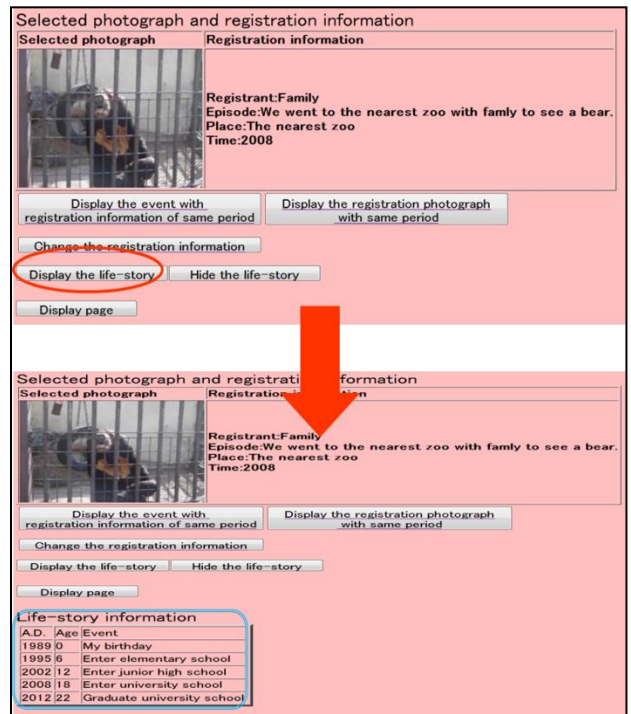


Figure 11. Example of dementia patient’s life story

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 (1: Strongly disagree, 2: Disagree, 3: Agree, 4: Strongly agree). 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 is difficult and there are many works, and 4-point means that it is appropriate.

a) Easiness to use the system

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 registration works for three databases in this system, we obtained feedback that "there are many works overall." Because registration works are carried out by hand and each registration content (photograph, events and life story) are input one by one. As mentioned above, extended activity will become heavy burden for persons with dementia and a person who had never used a personal computer before. Although the registration works are hard, it provides opportunities to communicate with persons with dementia during the registration process and recall various episodes which anyone does not know. Especially, when the users register about life story, they have possibilities to recall the memory of his or her childhood which family had never heard.

b) Efficiency of using memories

Regarding the efficiency of using memories, we obtained positive opinion that "memories are useful for supporting elderly persons, because they often talk about old times."

Some participants pointed out a very interesting possibility 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. This kind of difference may generate different attention according to gender of caregivers. In this experiment, all participants were men, and this possibility was not confirmed.

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. DEVELOPMENT STUDY

From the evaluation results, it is shown that using photograph and its information is useful to recall memory and promote communication with the person with dementia and family. In addition, it is found that life story is effective content as the recollection support function. However, there is still room for improvement of the function of the life story in this system. In this system, all the family including a person with dementia must input their life stories to the system. This task may be hard for the person with dementia. In addition, each life story is shown independently while the life stories of family are related to each other. Thus, in this section, we focus on the life story and propose the extended system.

In this system, all the family inputs their life story as they know. Based on the registered stories, the system shows the related life stories to the users. By comparing the life stories, they can take a communication through the found of the difference of experiences at the same age and the experiences before he or she met with spouse. In addition, by using the life stories of family, the system creates the life story of person with dementia because the person may not be able to recall his or her life story. Thus we propose the system that provides a place where each family sympathized with persons with dementia's memory.

A. Life Story

This section describes that why we focus on life story. Life story is formed by accumulated life log and life history. Diaries and albums are used to keep a record of personal life logs. However, these items may be lost due to disasters and accidents. And so recently, "digitalization of information," in which the data of diary and album are stored in computers, is progressing. In addition, by development of the Internet, a life log also has attracted attention as a communication tool, like Weblog and SNS (Social Networking Service). On Weblog and SNS, a user often writes a comment to registered photographs and then uses them to communication.

Life story of a person is a collection of significant events for the person, which may be not important for others. However, talking about a life story of a person with his/her family or friends becomes a tool of communication with others and understanding of difference perspectives. Through such communication about life story, a person can give meaning to its own life. Recently, talking about life story has attracted attention for integration of egos [11]. In this research, talking about life stories is used in group work. As studies which focus on the efforts for the individual, in [12], the personal narrative is pointed out to be necessary, and in [13], Blankenburg argued that if a log of life story does not specialize on individual then it may not attract others' notice. Personally characterized episodes are an important element of communication.

The human life generally will be long period until old ages from childhood, and so, elderly persons have various episodes in their life story. Elderly persons can talk about their rich experiences and find meaning of their life through the talking. Young persons who talk with elderly persons about their life stories compare themselves with the elderly ones, and consider their own lives. Thus, talking about the life story can be a communication tool for generations. In [14], it is shown that talking about life story is one of methods to understand the past well and it can apply own experience to the future.

From the result of section VI, it is known that elderly persons want to talk about their experiences, regardless of sex. Therefore, the extended system uses the life story to communication tools with persons with dementia and caregivers.

B. Research Trends

As a study using the life story, there is a system, called "yourStory" [15]. In this system, a user summarizes its own life story to recollect memory. This system focused on a "community" which users have been belonged in their lives. In this system, a community is defined as elementary school, junior high school, extracurricular activities and company etc., which are considered as organizations to which the most people have belonged. Many people belong to some communities, and people in a community have a common purpose and place. By summarizing events of a life story according to each community, the registered events may become a trigger of memory recollection of another event.

Figure 12 shows an example screen shot of this system. In this system, the horizontal axis is the time and the vertical axis is the communities which the user have been belonged. When the user click an area, the photograph and some episodes are displayed.

C. System Proposal

In development study, we propose a communication system with person with dementia and family caregivers by using their life stories. The system supports not only the registration of each life story, but also the share of life story and the comparison with other life stories, which is a trigger of communication and memory recollection. Then, the event of life story is classified to one in a period of a life, such as childhood, elementary school, junior high school, and so on. The user can compare some life stories in the same period, and find the differences of experiences at the same age. The life stories ordered in time is also shown.

In addition, based on the life stories of each member of a family, "family life story" can be created. Family life story consists of common and impressive events with family.



Figure 12. Example screen of your Story

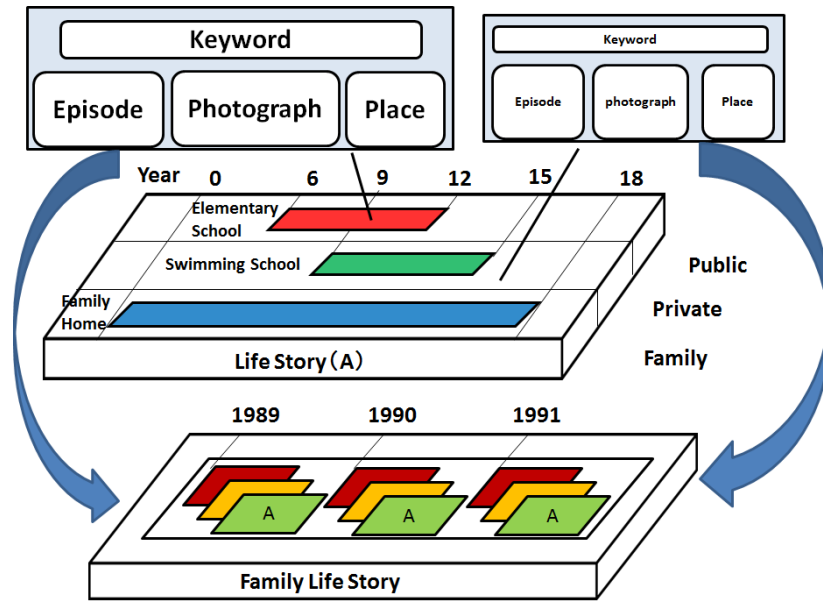


Figure 13. System image of the extended system

Table III. Example of Community

Community	Example	Category
Schools Education	Nursery school Elementary school University etc.	Public
Hobby Activity	Lesson, Club activity Volunteer body etc.	Private
Family life	Family home Apartment etc.	Family

In what follows, the details of the extended system are explained. Figure 13 shows the system image of our extended system. For each event of life story, its episode, photograph, location, community, time, and keywords are registered. The community is defined by the same way as the previous study introduced in Section VII-B. Communities are categories according to the Table III.

Next, how to use this system is shown.

- a) If there is the same community and keyword in the other users' life stories, all information about such stories are shown in the near area. Then the user can compare these life stories and associate with each

episode. Regardless of the similarity and differences of the episodes, talking about the memory and episode promotes communication.

- b) If there is the same community, but there is no common keyword in the other users' life stories, only the keywords and photographs of these stories are shown in the near area. That is, the details of episodes are hidden from the users. By hiding the episodes, the communication is done guessing the episode.
- c) If there is an impressive event in a life story for all the family, the user can create "family life story" by adding this event to family life story. The users can know the history of the family visually by filling in a blank of the family life story.
- d) If the person with dementia and his family caregivers cannot recall his memory, the system proposes his life story by guessing from the episodes of life stories of the family and the family life story. Through the communication based on this temporary life story, they can recall the true memory and modify it.

VIII. CONCLUSION AND FUTURE WORK

In order to realize the promotion of communication with persons with dementia and family caregivers, a new system is proposed that supports memory recollection by using photographs and associated information. The system supports the recollection of memory via information about a selected photograph and the related social events. By talking about them, the activation of family communication is aimed to be intensified. In this study, it is known that the life story of the person with dementia will be a good trigger of communication and memory recollection. Then, we also proposed the life story sharing support system to promote a communication with person with dementia and the family.

The next step of this study is to implement the extended system, and to evaluate the system with the help of persons with dementia.

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