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Author(s)	Takatsuka, Ryozo; Fujinami, Tsutomu
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Description	

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Aware Group Home: Person-Centered Care as Creative Problem Solving

Ryozo Takatsuka and Tsutomu Fujinami

School of Knowledge Science
Japan Advanced Institute of Science and Technology
1-1 Asahidai, Ishikawa, Japan,
ryozo-t@jaist.ac.jp, fuji@jaist.ac.jp

1 Introduction

The population of elderly is rapidly increasing in Japan and we expect that one fourth of our population are older than sixty-five years in 2020, which amounts to thirty five million people. The number of people with dementia, who need some types of care, is then estimated to be about three million, which occupies eight percent of elderly people. The change suggests that we can no longer hospitalize them, but have to find some way to go along with them at home.

Group Home is a type of caregiving for the elderly with dementia, where a small group of people with dementia, normally limited to five to nine, live together in a house and live their lives at their best with a help from caregivers. Group Home is thought to be ideal form of caregiving in the sense that the inhabitants can keep their contacts with the locals to feel at home.

Managing Group Home may, however, often run into troubles due to the cognitive asymmetry between the elderly with dementia and caregivers. The cognitive world of people with dementia is often inaccessible from cognitively normal people. Some people with dementia have provided us with their own witness[Boden 04], helping us understand what they think and how they feel. We are, however, afraid that they are rather exceptional. Most caregivers are often stunned at the strange behaviours of people with dementia, being unable to understand what they are doing.

We address in this paper the problems we found in the communication between the people with dementia and caregivers and present design principles for Aware Group Home, which enhances the awareness of caregivers towards people with dementia using information technologies.

The paper is organized as follows. Section 2 addresses the problem in communication with people with dementia. Following sections 3 and 4 present our attempt to get an access to cognitive world of people with dementia. Section 5 explains some results and Section 6 makes our approach clear.

2 Understanding people with dementia

Understanding a person with dementia (hereinafter PWD) is no more different than understanding a normal person. According to Situation Theory[Barwise 83],

meaning is conveyed as follows: Suppose there exists an action, a_1, by PWD. The action, a_1, is then categoraized into a particular type of act, T_1. We realize the content of his action by categorizing a_1 into T_1, which we express as $a_1 : T_1$, read as "a_1 is of type T_1." A person who moves his legs repeatedly to push his body forward is, for example, understood to be 'moving'. The distinction between a particular action and the type into which the action is categorized is of importance here.

Suppose that the PWD is a resident of a Group Home and he is moving to the entrance. His action then signals that he is going out, which we term as an action, a_2. For a caregiver, the PWD's action, a_2, is categorized as 'leaving' home, which might lead to an accident. The caregiver, therefore, tries to stop him before his leaving home. The caregiver's inference is schematically expressed as $(a_1 : moving) \Rightarrow (a_2 : leaving)$ to be read as "moving means leavning."

Let us now turn our attention to the cognitive world of PWD. Suppose that the PWD actually wanted to go home. His action of going out, a_2, must be understood as 'going home' from his point of view. The PWD's inference is thus as follows: $(a_1 : moving) \Rightarrow (a_2 : going - home)$ to be read as "moving means going-home."

We draw from the example above a conclusion that the caregiver and PWD are attuned to different sets of constraints, the constraints which give each action some meaning. Being attuned to different sets of constraints is a source of misunderstanding between them and the cause of troubles. The PWD is obviously angered if he is not allowed to go home no matter how well the caregiver tries to care the PWD. To understand PWDs fully, we have to attune ourselves to the same constraints to which PWDs attune themselves.

The difficulties in understanding PWD are addressed in two steps. The first step concerns the *categorization* of their behaviours and the second the set of *constraints* to which they attune themselves. We address each in the following sections.

3 Monitoring people with dementia at Group Home

It is often difficult to categoraize PWD's behaviours due to their limited cognitive abilities. Watching TV means, for example, to enjoy watching a broadcast program for normal people, but some PWDs lack the concept of broadcast and cannot distinguish things around them and events on-aired on TV. The levels of cognitive abilities vary among PWDs, thus caregivers have firstly to observe PWDs as much as possible to understand how they percieve the state of affairs surrounding them.

It is desirable for caregivers to observe PWDs, but requires a particular care in doing so. Most PWDs may notice the attention directed toward them even if they are cognitively disabled to some extent. Caregiver's attention may disturb PWDs and lead to unwanted outcomes such as anxiety. To avoid troubles, we have installed a set of video cameras on our Group Home for caretgivers to observe PWDs unnoticed.

We have installed six cameras in total; one at the gate, two in entrance hall, two in sitting room, and one in the kitchen. Figure 1 shows two cameras installed in the entrance hall. We have also installed an infrared sensor at the entrance to detect a visitor or resident.

The images obtained through these six cameras are monitored on two 14 inch displays, one of which is installed at the entrance and the other in the sitting room. Of six images, four images are chosen in turn for viewing due to the limited size of display. The movies filmed via these six cameras are also stored in a hard-disk recorder and ready for viewing for a week.

Fig. 1. Two cameras installed in the entrance hall

4 Creating a story people with dementia live

The second difficulty in understanding PWD is to understand the meaning of their behaviours from their own point of view. Our approach is to create a story a PWD lives, which is known as narrative-based care in the literature[Greenhalgh 98]. Here is an example of a male PWD, who often leaves our Group Home. Below is a case where the caregiver does not have an acquaintance with narrative-based care. The story is firstly narrated from PWD's point of view:

> **PWD's account:** Now is the time my son comes back home from school. He will be in trouble if I am away from home because his mother has already died. I enjoyed my stay here quite a lot. I have to hurry up to home now. Um... I am very tired and cannot walk. Eh, someone is calling me, but I cannot respond to him as I am in a hurry. He is telling me not to go, but I have to go. Oh, he is still following me. I have to run, but I cannot move my legs any more. God, I stumbled on a stone...

The same course of events can be narrated differently from a caregiver's point of view as follows:

> **Caregiver's account:** The guy is recovering and can walk longer than before although he use to be in bed, rarely going out, when he was at his home. I believe that asking him to do some daily work at Group Home such as wiping the windows has improved his health. But he may stumble if I do not stop him now because he is not fully recovered so as to go back home on his foot. He is about to stumble, but he tries to run away when I call him. I wish if he stopped now. Oh my god, he stumbled. No wonder, he was too hurry to walk.

The above story explains why the PWD stumbled in response to the caregiver's behaviour. The PWD receives the caregiver's behaviour as a threat. The incident was caused by the caregiver's ignorance of the PWD's cognitive world. The caregiver does not realize that it was himself who caused the accident because he attunes himself to a different set of constraints from those to which the PWD are attuned.

The things may change if the caregiver knows the PWD's story. Suppose that he understands the reason why the PWD left the Group Home by turning to the story. He can then play a role of onlooker until the PWD reaches the point where he can no longer walk. Once the PWD stops for a break, it is the chance for the caregiver to interrupt him by playing a role of someone with goodwill. If he offers a help, the PWD is willing to follow his advice, namely, to walk together to 'his' home, which is in fact the Group Home he has just left.

We have created a number of stories to each PWD. Each story observes the five rules as stated in [Greenhalgh 98]:

1. Narrative has a beginning, a series of unfolding events, and an ending.
2. Narrative presupposes both a narrator and a listener.
3. The narrative is concerned with individuals.
4. The narrative provides items of information that do not pertain simply or directly to the unfolding of events.
5. The narrative is absorbing.

5 Results

Only a few months have passed since we started our project, thus it is premature for us to induce any concrete conclusions supported with statistic data, but we

have observed some characteristics in the use of images available via cameras. A series of interview to five caregivers working at our Group Home revealed that caregivers with longer experience utilize the images more frequently than those with shorter experience. By 'longer' we mean the experience of more than four years. We call the caregivers with longer experience *skilled*, while those with shorter experience *novices*.

Through the series of intervie, we found the reason why the skilled utilize the images more frequently than novices. They are good at applying a story to understand the metanl state of each PWD. They frequently watch the images to know what residents are doing and how they feel. Novices, on the other hand, have little time to view the images. They have also difficulties in understanding the cognitive world of PWDs. We conclude from our observation that it depends on how well a caregiver can understand the meaning of PWD's behaviour how well she can utilize the images. The story helps caregivers decide when they should interrupt PWDs.

6 Person-centered care as creative problem solving

Before concluding the paper, we would like to make our approach clear by comparing ours with traditional one. People with dementia have traditionally been regarded as sick and a target of therapy. We call this traditional approach *medical model*. The problem of medical model is typically observed as a restriction on PWD's behaviours for the sake of cure. They may even be tied down to the bed so as not to do a harm to themselves or others at worst.

The reality is, however, PWDs are incurable for the moment, thus, it does not make much sense to treat PWDs based on medical model. Alternative is to place PWDs within social context and treat them as a person. We call this alternative *social model*. Our target is the person itself and we help him live a spontaneous life to his best. We have to, however, ensure him from accidents. The difference between these two models is summarized in Table 1.

	Medical Model	Social Model
Target	sickness	personhood
Objectives	therapy	assistance
Problem	restricted activities	life-threatening accidents

Table 1. Medial Model vs. Social Model

We argue that the cargiving for PWDs is a creative problem solving and no different from other scientific activities. As other scientific activities do, we start by collecting first-hand data by observing behaviours of PWDs directly or through cameras. Observing PWDs through cameras is preferred to direct observation on the spot because direct observation may change the behaviour

of observed, making it difficult for us to get an access to the real figures. We then make a hypothesis to explain why a PWD behaves that way, not the other way. With information available from other sources than cameras, e.g., a family history, we gradually construct a theory of his behaviour or his mental model. The theory is expressed in a form of story, which is easy to memorize and share among caregivers. The theory is validated through practice of caregiving and monitoring the results. A circle of knowledge creation is then complete, followed by new circle.

7 Conclusion

We have addressed the problems in understanding people with dementia (PWD) at Group Home. Video cameras installed on our Group Home have been useful for observing their behaviours unnoticed, but one has to turn to a story to understand the meaning of PWD's behaviour. A story allows caregivers to catch the best timing to interrupt PWDs for safety, thus contributing to PWDs' spontaneous lives. We found through a series of interview that experienced caregivers watch the images available via cameras more frequently than novices do. We think that creating and sharing stories among caregivers facilitate effective use of video images. We have also proposed to view caregiving as a creative problem solving process. We believe that technologies installed on Group Home should contribute to facilitating the process of creative problem solving as we described.

As a next step, we are concerned with families of PWDs. Keeping PWD and his family close may place him in broader social context. Distributing video images to families may strengthen their relationships and caregivers may also be benefitted from their interactions by obtaining the information of PWD which may otherwise be unavailable. The more items of information caregivers obtain, the better story they can create of PWD.

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