Creating Knowledge for Dementia Care

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Abstract

Growing number of people with dementia in Japan demands us to go along with them at home. We need to know who they are and why they behave that way for caring them appropriately. The process of knowing people with dementia may be understood as a particular case of knowledge creation. We can thus apply the knowledge creation theory to the issue of caring people with dementia. Visual information obtainable through video cameras is useful for getting an access to the cognitive world of people with dementia, but few other technologies are available to the end. Sensor networks currently under development may be useful to produce the evidence of good care.

1. Introduction

Japanese society is rapidly aging. Some research predicts that more than 21 percent of the population will be over 65 years old in 2008. More than one percent of the population is expected to suffer from some form of dementia if seven percent of the elderly, whose ages are more than 65 years old, suffer from dementia as is the case today. Some researchers expect the number of people with dementia will be doubled in 2045. Two percent of the population will be suffering from dementia if it is the case. We will face lots of problems if we do not take proper measures to cope with the situation, given the decreasing number of younger generations. Two of 100 people may be dementia in the aged society to come in 40 years. None of us can imagine how we will live in such a soceity, how we can support so many people with dementia.

People with dementia use to be hospitalized if the family cannot care him or her at home, that is, they are either accommodated into hospitals or nursing homes, but the growing number of people with dementia calls for some other forms of care-giving. Group home is a care house recently introduced into Japanese care system, where relatively small number of people with dementia live together with a help of care-givers. The group home we are involved in for example accommodates five or six people with dementia, who share a house with two care-givers. Group home allows people with dementia to continue their normal lives as much as possible. Figure 2 depicts the group home we are involved in. As is observed in the picture, our home is a traditional Japanese house with which the residents are familiar. People with dementia are thought to enjoy better care than the one often available at hospitals, where their behaviours are tended to be restricted by staff.

While the people with dementia enjoy more independence at group homes, the relation between the people with dementia and care-givers may become tensed because they are much closer than in hospitals, both mentally and physically. The tension between them may cause a lot of troubles at group homes. The behaviours of people with dementia may go beyond the control by care-givers, leading to unwanted accidents, if they are upset by the reaction of care-givers. The care-givers are also exposed to the stress if they are embarrassed with the strange behaviours of people with dementia. We are concerned with the tension between them and try to find a way to resolve the problem, ease their relationships so that they go along with each other.

We can only expect the care-givers to better understand the people with dementia, not the other way around. We cannot and should not expect the people with dementia to learn something new or to change their patterns of behaviours because they are lack with the capability. Our research question is then how better we can understand the people with dementia and how we can help care-givers to

Figure 1. Outer View of Group Home

do so.

Some researchers believe that they can solve the problem concerning dementia care once they have developed a system to locate them at home or have built into a house a sensor network to detect what they are doing. Such a system or sensor network may be useful for ensuring safety or for avoiding accidents, but dangerous situations are rare and most other daily behaviours are outside the scope. Anyone wants to live on his own once risks are removed. People with dementia are not exception. It is wrong to restrict the behaviours of people with dementia by employing information technology when they are safe. We are interested in finding the ways to relieve people with dementia of various restrictions traditionally imposed on them due to the lack of human resources to look after them as the next step after we have developed systems to ensure safety. The concept is expressed as *person-centered care* [4]. Our effort should focus on the person who requires our care, that is, what he or she needs.

In what follows, we develop our ideas for dementia care. We are concerned with the quality of life, not the safety issue as is often discussed in the field. We do not disregard the safety issue, but improving the quality of life for people with dementia is no less important than safety because the most part of their lives are free of danger and needed to be improved as much as possible.

The paper is organized as follows. Section 2 claims that understanding the people with dementia is more essential than collecting *know-how* for caring. Section 3 proposes to investigate the issue of dementia care within the framework of knowledge creation theory. We focus on tacit knowledge in caring people with dementia. Section 4 explains the process in which items of knowledge for dementia care are created. Section 5 discusses what knowledge we can share for dementia care and Section 6 mentions the use of information technology. We conclude the paper by examining the nature of issue we are dealing with.

2. Knowledge for dementia care

Two types of knowledge are recognized in caring the people with dementia. The first type of knowledge is about his or her personality, that is, the patterns of reactions in response to stimuli. We have to know who they are and how they behave under certain circumstances. The second type of knowledge consists of skills to effectively deal with the people with dementia. Such skills decrease the number of troubles between people with dementia and care-givers, resulting in the peace of mind on both sides and the improved quality of life for the people with dementia.

Skills require the knowledge about the people with dementia to be properly applied to them. Skills are useless unless care-givers have an access to the mental states of people with dementia because they may not be effective in changing their course of behaviours if employed unconditionally. Skills are context-sensitive knowledge and the mental states of people with dementia occupy a great deal of contexts. Understanding the people with dementia in depth is thus essential in caring them.

The prime knowledge for care is the knowledge of people with dementia, more specifically, the knowledge of their mental states or mental world they live in. One may wonder why understanding the people with dementia is so important in caring them. Not many people are awere of the

fact that how different worlds the people with dementia live in from the one we normally perceive. Very few sources of information are available concerning the cognitive world of people with dementia with a few exceptions such as the book written by Christine Boden [2].

Due to the loss of short term memory, it is often difficult for them to experience continuous self. They may not understand why they are there, who took them to the home, or what he or she is supposed to do until when. While they feel difficulties in realizing the situation they are cast in, they can recollect past events, often the important ones for their lives, because the long term or episodic memory remains relatively intact. We can imagine that they interpret the situation they are cast in by refferring to the episodes that might give a meaning to the situation. They might be living their past upon experiencing now.

We believe that it is impossible to improve the quality of life for the people with dementia without understanding their cognitive worlds. Their cognitive worlds are so different from ours that we cannot predict how they behave under certain circumstances without any theory of their mental states. The knowledge of their mental states or cognitive world they live in is thus of prime importance in caring them.

3. Understanding people with dementia as knowledge creating process

Creating knowledge for dementia care is to build a theory of mind concerning a person with dementia. One may ask how we can express the theory of mind and how to construct it in practice. Another issue is training. How can we educate a person so that he or she can read the mind of person with dementia? How does he or she learn to construct the theory?

The structure of knowledge creation for dementia care is no different from the one we recognize in other fields where items of knowledge are created by a person or organization. Creating knowledge for dementia care is thus a particular case of knowledge creation. We can therefore import the notions of knowledge creation theory into the field of dementia care without difficulties [6].

We extend the notion of knowledge in what follows, taking a slightly wider view than normally perceived in academics. The term of knowledge is tightly connected to analytical reasoning. Since the birth of cognitive science in 1950's, we have been accustomed to regarding intelligence as some form of computation. Knowledge is in the tradition regarded to be a representation, e.g., a set of rules or the expressions in first order logic. We do not make light of analytical reasoning, but it is just one aspect of intelligence.

Analytical reasoning is not enough to capture the functionality of our mind. As we sometimes realize in daily life, we human-beings are not rational creature. We are emotional, feeling an excitement or sorrow in our life, and are often derived to run a risk even if our rationality tells not to do so. We may suddenly recognize a hidden pattern in things. There are many things that are beyond rational explanation. All these hitherto disregarded aspects of our intelligence, if we can call them so, are of particular importance in the field of dementia care because people with dementia are often left with those types of intelligence although their analytical intelligence is severely damaged. They still can taste foods, can enjoy or cry. They have an emotional life and an ability of judgement. They can stil perceive the situation they are cast in and attribute some meaning to it although it is very different from the one we attribute to the same situation.

It is surprising that we exert the corresponding capability to understand the functionality of a particular type of intelligence. We have to feel the other's emotion to understand how he or she feels. We have to grasp the other's idea all at once to understand the intuition underlying the idea. We have to sense the other's cognitive world to understand how he or she perceives the world. We can employ words to explain these functionalities, but they are the end-products of interpretations, not the phenomena themselves.

Some feel uneasy when we start referring to something beyond words. They feel difficulties in accepting the idea that there might be some other aspects of intelligence that are not included in or covered by analytical thinking. The issue of dementia care however is a great challenge to our rationality or conception of it. As long as we adhere to analytical thinking, we never understand people with dementia. They remain to be inaccessible forever and we will never be able to provide them with proper care. We have to break the defence of analytical thinking to cope with the world of people with dementia.

4. Creating knowledge of people with dementia

Knowledge is the theory of mind about the people with dementia in the current study. A great deal of efforts is required to construct the theory because the mind of people with dementia works so defferently compared with ours. The process of theory construction consists of two parts, i.e., *perception* and *judgement*. In the first part we intuitively understand their cognitive world. In other words we sense how people with dementia perceive the world. In the second part we infer the cause and effect of their behaviours, compiling a story or seeking an episode to explain the reaction in broader contexts of his or her life. After compiling a story the care-giver plays a role assigned to him or her in the story to revise his or her conception of the person with dementia based on the reaction observed. A cycle of theory construction then is concluded to enter the next one. We explain each phase in detail in the following.

4.1. Perceiving the cognitive world of people with dementia

The first step to understanding the cognitive world of people with dementia is to understand how they punctuate the world they are embedded in. No one perceives the world as one, big object, but cut it into meaningful pieces to label them and people with dementia are not exception. The way they delineate their environment can however be very different from the way we normally do. Some trivial items such as slippers for example can attract their attention while we do not pay much attention to such familiar items in our daily life. Things may have different importance to them and the world appears very differently to their eyes. We have firstly learn to delineate the world as people with dementia do to get an access into their cognitive world.

The difficult point is that the ways people with dementia delineate the world may vary. Each of them constructs their own world to live in. We have to thus observe each person carefully. There is no general theory of mind as for the people of dementia. Each person is unique. Understanding the cognitive world of people with dementia can be lengthy process and requires close contact with them. We have to spend as much time as possible to see a personal significance of items surrounding the person with dementia.

The second step is to represent the situation in which the person with dementia is attracted to a thing or an event[1]. We may express the situation as a sentence such as 'The woman is touching the slippers'. Our process of perception is completed when we have represented the important situation in some other symbolic system such as language. Once we have mapped the situation in front of us to a particular type in some other representational system, we can process the items of information to appropriately react to it. In other words, we have to understand the meaning of their behaviours in our system of interpretation or language to appropriately react to them.

4.2. Judging what to do

In the third step, we infer the antecedent or consequence of the situation in front of us. The woman touching the slippers in the example above may stop touching shortly or hide them away into a shelf storing tooth brushes. The latter action may happen if she admits personal significance for the item. By reffering to the past events where slippers involved in and observing her facial and bodily expressions, we can predict to some extent how she behaves.

[1]The terminology of *situation*, *situation type*, and *constraint*, is strongly affected by Situation Theory [1]. Gibsonean view of information forms a basis of Situation Theory and we believe that the cognitive world and behaviours of people with dementia can be studied in the theory of information pick-up and attunement to regularity. Formalization in the framework goes however beyond the scope of the article.

What enables us to predict her behaviour is knowledge. Such knowledge consists of constraints that define what follows to a particular situation type. The validity of constraints are ensured by the regularity governing her behaviour. We can predict owing to the regularity that she will hide the slippers by reffering to a constraint such as 'If she touches slippers and shows a great interest to them then she is likely to hide them away into a shelf'.

We believe that experienced care-givers know of many constraints that govern the behaviours of people with dementia. Such knowledge must help care-givers appropriately deal with people with dementia. Knowledge of constraints is however not enough to prepare for proper set of actions because we cannot brutally enforce them not to do the consequent action. As long as she believes that the slippers are very important to her and wants to keep them in a safe place, she will never stop putting them into a shelf storing tooth brushes. If a care-giver tries to stop her by all means, she will be upset and tention arises between them, resulting in a quarrel.

In the fourth and last step of the cycle, we propose alternatives acceptable both to the person with dementia and the care-giver. In the example above the care-giver may persuade her to put the slippers into some other place which she believes to be safe. If she sticks to the idea of putting them into the shelf, the care-giver may simply wait for a while until she forgets about them. In any case it is important not to deny her intention and to be empathic with her, if possible, helping her to accomplish the goal she set herself.

4.3. Creating a story and playing a role

We tend to pay attention to the know-how or techniques for caring the people dementia. It is certainly nice if we could compile a set of rules defining how to react to a person with dementia under what circumstances. Comprehensible description of techniques is however impossible given the variety of our daily life. It is rather important to understand the reason why poeple with dementia behave that way. We need at this point a theory of mind as for a particular person.

The theory needs neither be formal nor scientific. It should be easy to understand and should motivate care-givers to appropriately deal with the person with dementia. For the purpose we employ a method called story-telling, known in the literature as *narrative-based care* [3].

A story explains a person's behaviour in a context, giving it a meaning. Suppose that a woman is often on the run, leaving a group home. For the observer not involved in her world her behaviour is simply an annoyance. Each time she leaves home someone must follow her to take her back. There will be a tention between them when she is stopped because she has a firm purpose to go out. She may have to go back to her home to feed her son as soon as possible

in her world. If we can recognize some meaning in her behaviour or understand the reason why she does it, we can be wiser in treating her.

Story enables us to attribute some meaning to an otherwise inconceivable behaviour of person with dementia. It is also important for a care-giver to be assinged a role in the story. If she is aware of her role, it would not be so difficult for her to plan a course of actions under a certain situation. If she is assinged a role of passer-by in the example above, she will not follow the person with dementia on the run, the reaction which only makes the situation worse, e.g., the person accelerates her pace of walking only to fall to the ground. The care-giver rather meets her from the direction she is walking in and offers her some help to take her to some safe place, which is in reality the place she has left a while ago.

5. Knowledge sharing for dementia care

The types of knowledge involved in dementia care are summarized as follows:

1. a collection of significant situations that require particular attentions
2. the inventory of situation types classifying significant sisutations
3. the constraints the person with dementia is tuned in
4. the story explaining the background of constraints

How are these items of knowledge stored and shared? We examine the method of knowledge sharing one by one.

The first two types of knowledge are concerned with perception. Storing and sharing these types of knowledge help care-givers perceive the real figure of the person with dementia. Firstly, a collection of significant situations are best recorded on videos. They may be a set of movies that recorded the moments when the person with dementia showed a significant reaction. The set of movies comprise an inventory of behaviours as for a person with dementia. Secondly, an appropriate explanation or a title should also be added to each movie to be useful as inventory. Indexing is also important. The viewer otherwise cannot extract useful items of information from the collection.

The last two types of knowledge are concerned with judgement. A guidance for caring as for each person with dementia will be useful, the guidance that explains a set of constraints the person is attuned in and describes his background as a story. We can also apply the techniques developed in Artificial Intelligence to modelling the constraints. Some knowledge of the type may for example be represented in production systems. If it is implemented, the care-giver can foresee what will happen while he is engaged in caring a person with dementia.

The story of a person with dementia can be represented in text. If we collect all the stories of the people we care for, we can share them by compiling them into a document, which may be electronically realized as a sort of web pages.

All the items of knowledge mentioned above can be integrated on a system. The basic items are the movies capturing the moments significant to care-giving. They are categorized according to the inventory of situation types. The user can view related scenes with the situation in focus by following a link representing a constraint or regularity. The user can read the story behind the scenes if he is interested in the reason.

6. Information technology for dementia care

We are heavily dependent on visual information in caring people with dementia at our group home. Figure 2 shows a monitoring system installed in our group home. Currently, six cameras record the activities in the home from different angles[2]. Sensor-network will be soon part of our life, but we do not expect that the information obtained through sensors will completely replace our effort of observing people because bodily expressions are so subtle and cannot be captured with the information technologies currently available. We can for example extract quite a few items of knowledge by looking at a face. We can get an access to his emotional state, infer his intention, and conjecture what he will do next moment. The quality of information available through current information technologies are for the moment too primitive to meet our end.

The information available through current information technologies are useful to produce the evidence of good care. Any good practice of caring has to be supported with a concrete evidence. The information concerning the locations of people with dementia and care-givers at home may be useful in this respect. We found in our recent research that people with dementia tend to move less when we employ the caring method based on the story using video cameras, indicating that they are in peace, feel comfortable.

Assuming that the safety issue is resolved with a help of information technology, the next step is to develop a system to improve the quality of life for the people with dementia. For higher quality of life, people should be allowed to be spontaneous and be helped towards accomplishing his or her goal. Understanding people with dementia from their perspective is essential, but no technological help is available for the moment. Only man can understand man. Technologies will better be utilized to produce evidences that lead us towards better caring methods.

[2]Detailed explanation is given in [6].

Figure 2. A monitoring system installed in the group home

7. Conclusion

We claimed in this paper that understanding people with dementia, especially their cognitive world, is most important task among all and that all other caring skills are dependent on our understanding of people with dementia. We explained how we construct the theory of mind as for people with dementia and how to share it among care-givers. Story is the central concept and the usefulness of visual information is discussed.

Caring people with dementia is not analytical task. Both body and mind are engaged in the task. Perceiving the cognitive world of people with dementia requires good sense and intuition. Our understanding of their mental world and the way it proceeds goes beyond analytical explanation. Judging what to do in caring people requires broad variety of knowledge and empathy. Only the items of knowledge as for the constraints people with dementia are tuned in and their background stories can become the subject of analytical thinking. Emotion plays an important role in bridging the gap between the person with dementia and the caregiver. We regret that we had to skip the issue of emotion here due to our lack of knowledge.

Carl Rogers, the initiator of client-centered therapy, once asked Michael Polanyi whether it is possible to establish the science of man [5]. They did not know the answer. We are in the same position as they were when they ended their discussion, where Rogers claimed for *knowledge* of man in a concession, giving up with using the term, *science*. Half century passed since then, we encounter the same problem in differnt context, i.e., possibility of scientific knowledge of people with dementia. The theory of knowledge creation may cast a new light on the issue, extending our conception of science.

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