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Dialogue Approach to the Exclusive View towards Elderly People in Dementia Care

Abstract

In this thesis, we explored the way which led people, especially the young ones apart from the elderly, to empower their ability to respond to the elderly with dementia and argued how the productive knowledge of art and technology could contribute to empowering their response-ability. In the field of dementia care, we concentrated on the problem with the social exclusion of elderly people. The purpose of our study was to develop a methodology for resolving the segregation of generations and improving the social view towards the elderly with dementia.

The growing number of elderly people invites the rapid increase in the number of the elderly with dementia. Care of people with Alzheimer's or other forms of senile dementia thus requires immediate attention in Japan. With the growth of importance of a preventive approach to dementia, it also becomes urgent to cure the underlying problem of stigmatization. The elderly with dementia could be seen as outcasts; people who did not try hard enough to prevent it. Stigmatization is not a problem of individuals but that of society. The notion that people must not become demented has been wide-spread. Elderly people are driven by this notion as a norm. In this situation, they are targeted for marginalization and poor images towards them may remain in the society. It was pointed out that the social position of elderly people has systematically undermined and they were channeled from the main stream of social life. They were thus devalued and ageism became the focus. From the viewpoint of knowledge management, it could be regarded as a crucial reason for the deterioration in their importance that elderly people lost the value of their knowledge gained from experience, with the growth of scientific knowledge based on the development of technology. As long as knowledge is the source of values, it becomes an issue to be counted to manage the implicit knowledge of elderly people. We focused on their memory and made use of it by means of the art of dramas in order to create the value of aging.

In the role theories, which are based on the individual identity, we concentrated on the idea of community or common world in which a kind of contribution to the society afforded only by them could be found. The remarkable example that encourages such kind of community is the reminiscence theatre, which is the meaningful link across generations. As our research strategy, we applied a participatory action research to an inter-generational communication project that aimed to construct a social system in which a children-centric community for dementia care was created by utilizing dramatic arts produced from the memory of elderly people. On the other hand, we also took a case study on privacy concerns at a group home in another project that developed a monitoring system using video cameras to support the elderly with dementia and their caretaking staff. While taking up the themes of privacy, human rights of the elderly to live safely and freely and their staff's responsibility, we discussed the concerns that by the intervention of such information technology as the system with cameras, the intimate relationship between them must be interfered with. It became an issue in the development of the system if the utilization of technology deprives the elderly of the relationship with the others. The fundamental problem in our study was the management of techne as productive knowledge.

In our action research, we conducted a project involving both elderly people and children, drawing up the curriculum in a primary school. In the inter-generational communication project, we developed the approach of fostering their dialogue through performance as a kind of dramaturgy and investigated the children's conception of the elderly with dementia. Primary school children performed creative dramas based on the memories extracted of the elderly without dementia and communicated with the elderly with dementia by means of the dramas. Focusing on the theatre play as a kind of story which might attract people, we designed a model of the social system in which a community that consists of the members who have willingness to be involved with and their enhanced response-ability to the elderly with dementia. Through the project, we verified that the story compiled by children functions as an interface between the children and the elderly with or without dementia for facilitating their communication. It was shown by statistics that the images of children upon the elderly with dementia changed to more positive ones after evoking and receiving their memory through the session by the drama. Meanwhile, during the preparation of that drama session, the children learned and understood the objective characteristics of dementia as a disease by our medical explanation in which we also urged them to focus on the personhood of the patients.

It was found, however, that most of the children expressed in a written survey that they felt pity on the demented elderly and even felt fear about being demented. Designing a series of dialogue-based educational programs, we made a way to cure this fear and broaden their view towards the elderly. We also recognized the limit of one-way explanations of dementia and that we needed to help the children consider and realize how to relate to the elderly by themselves. We introduced the program that stimulates the imagination of the children. The program helps them to imagine how they would live in the society and what kind of difficulties they would experience if they became demented. It also helps them to consider how to communicate with the elderly and to be involved in the society. The research utilized some fairy-tale stories in order to make the dialogue among children and the goal was to verify how the stories work in the dialogue and stimulate the children. The children presented negative opinions about aging at the beginning of the dialogue, but their attitude underwent a transformation. By imagining and playing the character in the fairy-tale story, they began to present positive opinions of the way to live after they became old. They were in a position to think about the situation where the elderly with dementia were, so they could find the way to communicate with the elderly. And by interpreting the meaning of the story, they were afforded opportunities to broaden their view towards aging. Thus, it turned out that the story is an effective interface that leads children to an exploration of their involvement with the elderly with dementia.

We focused on the story which bridges the gap between children and the elderly with or without dementia and utilized the story of creative dramas and the one of fairy-tales in the preparation for the reminiscence session by means of dramas. We proposed to employ a story as an interface for the inter-generational communication and named this approach "Story Interface" that evokes emotion, inspires imagination and leads to reflective thoughts. As for the interface design, the concept of emotional design of things was presented in cognitive science. We originally extended the concept to social events and proved that it could be applied to the design of social system. We also proposed the concept of performable social innovation (PSI, or Performative Innovation) for creating the value of aging by pursuing the performability of stories, which led children to thought in action. The concept of PSI consists in enhancing the ability to judge called insight or phronesis as a deliberative kind of action-oriented knowledge, which guides people to the common good in its performative enactment, functions in the presence of others and has the roots in common sense.

The concept of PSI was developed from that of responsible social innovation (RSI) by empowering the response-ability to the elderly with dementia. From the perspective of technological RSI, we investigated the problematic case of group home at which the monitoring system with cameras was utilized and shed light on the closed nature of the site of dementia care. The development of the system was brought to a halt, due to privacy concerns on the ground of the right of freedom for the elderly. There was an assumption that private space covers the whole of a care site as their home. The form of group home was adapted in the deinstitutionalization of care environments and a certain domestic intimacy became to be required. It is a worthwhile indication by philosopher Hannah Arendt that while as the opposite of the social which controls conformably the behavior of members, modern privacy in its most relevant function to shelter the intimate was discovered and has been estimated positively, the privation of privacy lies in the absence of others and its nature has hardly transformed. The site of care enclosed as a sphere of intimacy, the social services applied within lack transparency and the residential elderly are deprived of seeing and hearing by the others.

Against such danger of hiding and confining the elderly as the rise of neglect, abuse or accidents, we advocated their right to be carefully watched over and to choose among care facilities provided with or without the system by presenting a paradoxical viewpoint that it helps the elderly to retrieve the freedom of encountering with the others. We took a point that the system gives caretakers a new way to empower their responsibility to the elderly and accountability to the others without by ensuring the transparency of care site and making their judgment verifiable. The management of technology makes it possible for not only the staff but also such other people as their family or a third party advocator to be partially unshackled from the constraints of space and time, to participate in taking care of the elderly and to perceive the site to be credible. There was also a concern that the camera-mediated objective approach interfered with building closer ties with the elderly. In the combination with epistime as scientific theoretical knowledge that avoids the subjective involvement with objects, technology in one way tends to deprive people of their mutual relationship. Meanwhile, it helps the elderly to secure the place to form the relationship with the others without as well as within their residence, enhancing the staff's ability to judge for providing them with the best support. In reference to Aristotle's distinction of three types of knowledge, we argued the ambiguity of techne in making its combination not only with epistime but also with phronesis.

Finally, we concluded that art and technology derived from techne could contribute to establish the common world in which the appearance of the elderly to be seen and heard could be guaranteed. Even though the development of techne as productive knowledge promotes efficiency and works to exclude elderly people from the society, it has another aspect. Its management provides a chance with caretakers to respond deliberatively to the call for care of the elderly with dementia and a way to ensure their publicity against the closed nature of care service. On that basis, the elderly with or without dementia are in a position to reconstruct the inter-subjective actuality of the world across generations. As long as their audiences exist, elderly people can help the other generations build the world that transcends the life-span of individuals. Managing the art of their memory activates inter-generational story-telling and leads children to have positive conception of the elderly with dementia. The response-ability of children to the elderly can be enhanced through performing the stories both of creative dramas and fairy-tales. It becomes our future work to develop the inter-generational interface by designing the stories for dialogues and the non-verbal way of communication in dramas. It is further required to organize the metadata of information from which the memory of elderly people can be extracted for the sake of incubating innovation to create the value of aging by managing and transmitting their knowledge. As for the ethics of managing information technology for the elderly, the design of dialogue among citizens becomes an urgent issue.