# Finding "Commensurable" and "Communicable" Meanings in People with Dementia

Kazumi OH (swandiamonde@hotmail.co.jp) Graduate School of Letters, Kyoto University

#### 1. Introduction

This thesis attempts to pursue and envisage a concrete pathway in the system of a "mutual" recognition (="commensurability") between caregivers and residents (=people with dementia) by examining the group-care practice at Japanese S hospital and nursing home for people with dementia (=S hospital and nursing home) in a broader socio-political context in Japan. The value of the property and the cost of care at S hospital and nursing home are not special. What does make it stand out is, for example, when you enter one of the 'houses' at S hospital and nursing home you sometimes find the smell of coffee hanging in the air. S hospital and nursing home is a space where the 'daily-life sphere' is constructed.

While many sociologists have discussed the relationship between the health care professional and the patient at the point of its one-way asymmetry, some sociologists have tried to recommend alternative medical care or social welfare. The point of departure for this thesis lies in neither the unconditional affirmation of western modernized medical professional knowledge, nor in anti-western modernism, rather it is from a third way. In this thesis I show nothing but my appreciation of S hospital and nursing home's challenging group-care practice in which western modernized medical space and the 'daily-life sphere' are bridged to create a new relationship between caregivers and care-receivers. The fabrication of S hospital and nursing home which aims to perform norms and values in 'daily life' has led caregivers to initiate pattern-making practices to embrace and operate by a particular form of the 'contested sympathetic cognition' for people with dementia. Therefore, the 'daily-life sphere' is the sociological analytical term for projecting the reorganization of medical care and social welfare in western modernized areas and countries.

Although the 'contested sympathetic cognition' at S hospital and nursing home is caregivers' one-way cognition, we can admire the "commensurability" between caregivers and people with dementia. Certainly, what has been done by caregivers towards people with dementia at S hospital and nursing home has been forged by applying the one-way asymmetrical relation that has been revealed in the context of reflection and criticism of medicalization in western modernized areas and countries. However S hospital and nursing home's caregivers have succeeded in new positive

relationships with people with dementia. In the past people with dementia have been considered to be incommensurable in a one-way relation with their caregivers. At times, they have been segregated, treated medically badly and deserted. On the other hand, people with dementia at S hospital and nursing home are expected to be "commensurable." This is in stark contrast to the way people with dementia used to be treated. 'Daily life' fabrication and pattern-making practices in S hospital and nursing home provide the "commensurability" between caregivers and people with dementia to caregivers. Its seismic impact on caring can be upheld by the caregiver's individual construction of the "commensurability" between caregivers and people with dementia in the 'daily life sphere.'

## 2. Cognitive Structural Analysis of Group-Care Practice

# 2-1. The 'Medical Cognition' of Dementia and Anti Medical Care Practice

The primary factor that has forced people with dementia to be secluded, to be poorly cared for medically or to be abandoned is western modernized medical professional knowledge. People with dementia have been imposed with isolated, medically ill treated or neglected lives because of the diagnostic accounts of their brain atrophy or porencephalia. When we call this type of cognition 'medical cognition,' the strongly influential 'medical cognition' has worked in western modernized areas and countries to make the motion of separation and restraint for people with dementia valuable. Due to the medical technical development of brain visualization in the 1980s, the 'medical cognition' was reinforced and the utterances and actions of people with dementia were deemed problematic. Under the 'medical cognition,' demented symptoms seem to be unchangeable and people with dementia are absolute patients. The 'medical cognition' has been endorsed within medicalization in western modernized areas and countries.

However, since the 1990s it has been recognized that demented symptoms can change in accordance with their situational surroundings and relations with carer(s). This has attracted attention in western modernized areas and countries. In some cases demented symptoms have died down without medicine. When we call the cognition of people who are attracted by the notion that demented symptoms can be changed in accordance with their situational surroundings and relations with carer(s) the 'linkage cognition,' within the 'linkage cognition' people with dementia are not always patients.

While it is true that the 'medical cognition' and the 'linkage cognition' have been argued as having an opposing relationship (Iguchi 2007), these two cognitions are not always opposite in care-practice. Carers who are eager to promote the social aspects of people with dementia tend to complain about medical thinking and its ill treatments. Cruel medical treatments like giving too

much medicine and the use of physical restraint on people with dementia are strong incentives to improve caring. However, carers who complain about medical thinking and its care treatments, in fact complementally execute the 'medical cognition' and the 'linkage cognition' in practice.

## 2-2. Two Complementary Cognitions about People with Dementia

The 'medical cognition' and the 'linkage cognition' have a complementary connection in care practice. Iguchi Takashi has reflected on this (2005; 2007). Iguchi mentions that the 'medical cognition' is one of the notional options to understand dementia or the meaning of people with dementia's utterances and actions. Iguchi explains both the 'medical cognition' and the 'linkage cognition' are among the variations of the 'linkage cognition' and are placed at opposite poles (2007). According to Iguchi the 'medical cognition' is sometimes helpful for a family caregiver to exempt oneself from considering what people with dementia do and say (2005; 2007). For example, family carers that are willing to accept family with dementia can tentatively think dementia causes their family to make strange utterances and actions. As long as a family caregiver has the will to accept what family with dementia do and say, the 'medical cognition' works to purse the one-way recognition of people with dementia without asking validity of interpretation about the meaning of people with dementia's utterances and actions.

### 2-3. The Formation of S Hospital and Nursing Home's Group-Care Practice

Basically S hospital and nursing home supports the 'linkage cognition,' but the 'linkage cognition' is modified in a complicated manner. Once the 'linkage cognition' is chosen in group-care practice, caregivers consequently give up the 'medical cognition' and the complementary relationship between the 'medical cognition' and the 'linkage cognition' seems to end. Iguchi obtained his analytical notion from caring as family business. To make the latent relationship between the 'medical cognition' and the 'linkage cognition' in group-care practice visible, I propose a new cognitive concept that is equivalent to the 'medical cognition,' and secondary to the 'linkage cognition.' To refine the new cognitive concept I use what Kisuyo Kasuga said in her study about group-care practice, as follows (2003): "Emotionally controlled labor seeks to feel sympathy with, accept and realize what people with dementia want." The notion that caring is an emotional work of labor is key to the discussion that tries to enhance the societal and economical position of care-giving labor. The institutionalization of medical care or social welfare for people with dementia carries on patient-centered caring that the 'linkage cognition' comes from. Kasuga picked up the practical training of a Japanese nursing home based on the 'linkage cognition' and disputed

that excess emotional control and mental burdens impose on care workers. Kasuga continued to say that to show complete receptivity is to discern exactly what people with dementia want. However, in Kasuga's study, while showing sympathy is the same as giving receptivity, it remains unknown how we are to discover the exact wishes of people with dementia. Fundamentally, in general, understanding is not always the tool for receptivity and receptivity can be without understanding.

The relationship between caregivers and care-receivers bears the character of reciprocity. Reciprocity is not fair trade. Because there happens to be pride-betting trade between caregivers and care-receivers, relationships in caring are always unfair (Goto 2005). Caregivers look down on care-receivers and look up to care-receivers. Care-receivers look down on caregivers and look up to care-receivers. It is not fixed but changeable. It is often the case that the more the care-receiver needs the more the caregiver is moved in their mind.

To provide their fullest receptivity to people with dementia, S hospital and nursing home's caregivers, including nurses and doctors, artificially create the 'contested sympathetic cognition.' In order to achieve the "commensurability" between caregivers and care-receivers, S hospital and nursing home's caregivers treat the people with dementia as 'daily-life-conductors.' In the 'contested sympathetic cognition,' caregivers do not need to communicate with people with dementia as they do with the 'medical cognition.' On the contrary, despite their one-way approach caregivers at S hospital and nursing home can partially understand the meaning of people with dementia's utterances and actions under the 'contested sympathetic cognition.' Though the 'receptive cognition' cannot lead S hospital and nursing home's caregivers to understand the meaning of people with dementia's utterances and actions like the 'medical cognition,' it can prompt caregivers to display complete acceptance of people with dementia.

#### Formation of Cognitive Arrangement in Group-Care Practice and the Relations with its Prototype

The 'Linkage Cognition'	
Understanding: ○ Acceptance: ○ Communication=Com: ○	
The 'Contested Sympathetic Cognition'	The 'Receptive Cognition' (=The 'Medical Cognition')
Understanding: ○ Acceptance: ○ Com: ×	Understanding: × Acceptance: ○ Com: ×

(O: Positive X: Negative)

Note: One-way approaches from caregivers are included within communication.

Thanks to the complementary relationship between the 'contested sympathetic cognition' and the 'receptive cognition' S hospital and nursing home's caregivers accomplish the "commensurability" between caregivers and people with dementia. This "commensurability" brings about better 'linkage cognition' among S hospital and nursing home's caregivers' minds.

I exemplify the detailed pathway to the "commensurability" between caregivers and people with dementia at S hospital and nursing home showing the data I have collected from December of 2007 to March of 2008. At the very beginning of my research, I was just a guest. After people with dementia identified me as a caregiver I intended to display myself as a caregiver. There were several chances for me to help people with dementia, for example, changing underwear, taking them to the bathroom, and spending the nights with them. Staff and caregivers at S hospital and nursing home were very helpful, and I was able to do vast research with their cooperation.

## 3. Construction of the 'Daily-Life Sphere' at S Hospital and Nursing Home

## 3-1. The Formation of S Hospital and Nursing Home's Group-Care Practice

In general, all the strange actions (="problematic actions") can be understood if presumable situation and context are able to be applied. At S hospital and nursing home, the patterned situation and context which are organized by 'daily-life conductor' stereotypes enables caregivers to easily distinguish strange actions of people with dementia from "ordinary" actions, and to react spontaneously. 'Daily-life conductor' stereotypes make "healthy" and "usual" people the regulations and values present at S hospital and nursing home. The 'daily-life sphere' is strongly influenced by present Japanese "common sense." Without events like group-exercises or group-activities, caregivers at S hospital and nursing home succeed in keeping and raising the stability of patterned situation and context.

Patterned situation and context are the resources of contested sympathetic cognition at S hospital and nursing home. Of course, caregivers at S hospital and nursing home do not realize that they are handling and reacting smoothly to the strange actions of people with dementia. It is not their intention but the result of group practice. Then, I explain how to construct 'daily-life' patterned situation and context from what caregivers at S hospital and nursing home allude to as their unique way of care; appointing small units, hearing care-receivers' life histories, and reproducing the old days.

### 3-2. Appointing Small Units as 'Daily-Life Sphere'

First of all, in regards to appointing small units, S hospital and nursing home consists of

individual 'houses.' This type of care is called unit care in the field of social welfare. Unit care at S hospital and nursing home is sophisticated. Each 'house' has its own name and some 'houses' have mailboxes near the entrance. Each 'house' has its own family budget. At least once a day care-receivers arrange their meals and dishes together with caregivers in the kitchen. Care-receivers do not take any medicine for dementia. Due to bad conditions, most care-receivers have rejected other hospitals or nursing homes. Care-receivers are able to take part in domestic duties whenever they would like to.

Of notable difference here is that caregivers at S hospital and nursing home divide visibly and invisibly its space into several sections to conform to Japanese spatial partiality between public areas and private areas. Caregivers are acutely aware of being sensitive to this. In living and dining areas, caregivers are prohibited from managing dirty things like nappies because these are public areas. When a care-receiver appears in a public area wearing pajamas, caregivers ask the care-receiver to move to a private area to change their clothes.

Caregivers at S hospital and nursing home create a 'sphere of daily life' where present Japanese "common sense" prevails. At first glance, the norms and values of S hospital and nursing home's 'daily-life sphere' express that of "healthy" "ordinary" Japanese people as opposed to that of person-centered care. When a care-receiver rejects being shaved or manicured caregivers proceed with it. Caregivers rewash the dishes and chopsticks after care-receivers have finished washing them.

Consequently, seemingly caregiver-centered care is harmonized with person-centered care. The 'daily-life sphere' works to hide medical and institutional situation and context. In the 'daily-life sphere,' hygienic norms and values are embedded within the 'daily-life' customs. Caregivers believe that the 'daily-life' customs are indispensable to maintaining care-receivers' safety and wellbeing. In the precedent cases, caregivers judged shaving or manicuring as important to care-receivers' safety, and the dishes and chopsticks touched by unclean care-receivers' hands as harmful to care-receivers' health. Even if a quarrel or a tiny brawl occurs between care-receivers, malleable quality of the 'daily-life sphere' would be applied. So long as the 'daily-life sphere' is the place where people live together, some quarrels or tiny brawls may happen among residents who have different domestic and cultural backgrounds.

Whereas the 'daily-life sphere' is the base of the "commensurability" between caregivers and care-receivers at S hospital and nursing home, to improve the one-way 'contested sympathetic cognition' into "mutual" communication process it needs the complementary relationship between the 'receptive cognition' and the 'contested sympathetic cognition.' So far as the caregivers'

'contested sympathetic cognition' solely requires stereotypical acceptance towards care-receivers nothing like "mutual" communication has happened between caregivers and care-receivers.

## 3-3. Hearing Care-Receivers' Life Histories and Reproducing the Old Days

In order to attain "mutual" communication, caregivers at S hospital and nursing home listen to care-receivers' life histories and help them reproduce the old days. Listening to care-receivers' life histories is one of the original psychological therapies known as recollection therapy in the field of social welfare. According to this theory, elderly people are able to positively affirm their lives by sharing their life history. At S hospital and nursing home, caregivers utilize this theory to understand people with dementia as well. Caregivers at S hospital and nursing home trust the notion that people with dementia contain "previous" well-embodied memories. As to the peculiar behavior of a care-receiver collecting pieces of waste paper and rubbish, caregivers at S hospital and nursing home were able to explain that this was because Japanese society was very poor when the "elderly people" were young. When a crippled elderly lady stood to stretch her spine in an unusual form caregivers thought this was from wearing a 'kimono' (Japanese traditional wear).

Reproducing the old days crystallizes the process of understanding people with dementia. On the one hand, caregivers put the private belongings that care-receivers used before entering S hospital and nursing home around each private area or public area, for example their own favorite dressing table, family Buddhist altars, rice bowls, chopsticks and shampoos. On the other hand, caregivers put the goods that "elderly people" used in their teens or twenties around public areas. You can find a 'kuro-denwa' (vintage Japanese black home telephone), the picture of Emperor and Empress Showa and a wall clock. Vintage chests of drawers were presented from the neighbors. In some houses everybody could enjoy being seated on 'engawa' (veranda equipped along Japanese wooden houses) and 'kotatsu' (Japanese heater tables) on 'tatami' (straw mats).

Reproducing the old days powerfully empowers caregivers when two contradictory situations or contexts exist within the same care-receiver. For example, one moment O-san was crying out looking for her late husband claiming that he was missing, and the next moment she was whispering that she knew her husband had already passed away. To help with their interpretation about care-receivers' intention and will, caregivers grow to understand by way of stereotypes like "elderly people," "their younger age," "males and females," "Japanese" and "patients." In O-san's case, even the caregiver who was terribly confused about O-san's condition at the beginning withdrew their conclusion that the best thing they could do for O-san was to communicate and keep in touch with O-san until she was familiar with her state of confusion. The reason why the caregiver had

this change in conclusion was that three months later the caregiver heard other caregivers share that the demented symptom of O-san was witnessed just after O-san had lost her best partner. Referring to "females" and "elderly people" caregivers gave the valid interpretation that O-san tried to domesticate her "reality" by coming and going between past and present. The matter was not whether it was real or not, the matter was that caregivers can trust the possibility that there might be different accustoms and ways from days gone past that they can apply to the situation and context at S hospital and nursing home.

At S hospital and nursing home caregivers estimate that "previous" embedded memories of "elderly people" complete their "golden days." When the elderly person is female, caregivers presume her "previous" embedded memory is her "sweet sixteen." When the elderly person is male, caregivers suppose his "previous" embedded memory is "in the prime of life." Theoretically nobody knows the exact age of "previous" embedded memories of "elderly people." The reason why caregivers think this notion is trustworthy is that people who embrace any feeling of being lost or confused wish to maintain their pride. This argument comes from recollection therapy in the field of social welfare. To conclude, the findings from hearing care-receivers' life histories are connected with medical stereotypical cognition for people with dementia.

### 3-4. Sharing Patterned Situation and Context among Caregivers

The effect on caregivers from hearing life histories gives both reference for the meaning behind peculiar remarks and behaviors of people with dementia, and reference for suitable manners for reinforcing the caregivers' observations. As I already mentioned, caregivers' first priority is the daily health and safety of care-receivers' lives. Caregivers at S hospital and nursing home earnestly watch care-receivers' (bodily) trifle differences to catch anything wrong with care-receivers' (body). In other words, caregivers at S hospital and nursing home are watchful to distinguish anything unusual about care-receivers' from their average patterned (bodily) condition.

This daily standardization does not contradict observational sight within caregivers' practice for hearing care-receivers' life histories within the 'daily-life sphere.' However these double observational frameworks allow the training and discipline to understand the intention and will of care-receivers, hidden just behind their utterances and behaviors. The caregivers' findings about care-receivers' lives are not unique due to group-care practice. Caregivers at S hospital and nursing home observe what care-receivers do and say in a watchful manner, and share their findings. They exchange information gathered while they chat while dining, cooking, cleaning and washing, and as they collect daily schedules, medical and physical records.

Therefore, caregivers at S hospital and nursing home desire to modify care-receivers' deviant character mobilizing standardized patterned 'daily-life' situation and context. With ease, they pick up care-receivers' deviant utterances and behaviors that are the reverse of the 'daily-life sphere' where "healthy" and "usual" people's regulations and values prevail. They are inclined to make excuses that people with dementia are keen to be proper, because 'the greatest common devisor' between caregivers and care-receivers is being the 'daily conductor' at S hospital and nursing home. This is the function of the 'contested sympathetic cognition.' When a male elderly person spoiled his pants, caregivers argued that the size of his underwear was wrong. The caregivers' interpretation was as follows. Because the male elderly person was upset about spoiling his pants, it made the situation and context worse. Caregivers are accustomed to responding as they would do with an "ordinary" Japanese person. Because of the function of the 'daily conductor,' it is not the care-receivers' pride but the caregivers' pride which is at stake. The male elderly person and caregivers were accomplices as the executors and observers of present Japanese "normal" regulations and values.

### 4. Caregivers' Reflection on Communicating with People with Dementia

The minimum condition of "mutual" communication between caregivers and care-receivers is that there must be the process for caregivers to observe care-receivers reacting with the awareness of caregivers' intention and will. Within the situation and context of S hospital and nursing home, the primary caregivers' intention and will determines artificially manufacturing the 'daily-life sphere' for care-receivers. Caregivers at S hospital and nursing home report that care-receivers react to caregivers' intention and will by talking about the artificiality of their care practice itself. This situation and context is the beginning of communication between caregivers and care-receivers.

The following two points sum up the artificiality of S hospital and nursing home's caring. The first point is the patterned situation and context of the 'daily-life sphere' where stereotypical average "healthy" and "ordinary" peoples' regulations and values function. The second point is the caregivers' one-way acceptance of people with dementia where the 'contested sympathetic cognition' and the 'receptive cognition' are well engaged to guarantee 'the greatest common devisor' between caregivers and care-receivers. In relation to the second point, caregivers identify the 'medical cognition' that caregivers might abolish. The more deeply they reflect on how their 'contested sympathetic cognition' as well as their 'receptive cognition' are fundamentally nearly the same character as the 'medical cognition,' the more fiercely they grasp the "commensurability" between themselves and people with dementia.

A young caregiver at S hospital and nursing home reflected on her experience as follows. "I was scared of being engaged by N-san. When N-san talked to me, I greeted her and ran to G-san's room. Because I was so terribly sorry I couldn't concentrate on G-san, and just nodded and responded to G-san's friendly conversation saying 'Yes, yes, yes.' G-san said to me 'You just repeated "Yes, yes, yes." As I felt sorry for G-san, G-san kindly said 'Being strained must be tiring, is it?' Tears fell from my eyes. Her words remain etched in my mind. I thought this is the experience of being healed by 'elderly people.'" In the above example, the relationship between caregivers and care-receivers is reversed. When a caregiver is conscious of this reversed relationship they become aware that the notion of "commensurability" between caregivers and care-receivers can truly exist. However, it is rare for caregivers to be able to admit their faults that preclude the notion to see people with dementia as a communication partner. This is when caregivers are able to internalize the "commensurability" between themselves and people with dementia.

#### 5. Conclusion

This thesis precisely depicts the system of 'daily-life sphere' that realizes a "mutual" recognition between caregivers and care-receivers within a medical and welfare institution from the point of caregivers' structural cognitive arrangement. The 'daily-life sphere' at S hospital and nursing home completes not the asymmetric relations between patients and medical health care professionals but the "commensurable" and "communicable" relations between caregivers and care-receivers.

The analytical framework from caregivers' structural cognitive arrangement is completely different from that of the channel of communication between caregivers and care-receivers focusing on caregivers' and care-receivers' individual ability, mental condition and its relations. Nowadays the analytical framework for the channel of communication between caregivers and care-receivers is dominant in both academic studies on dementia or people with dementia and the institutionalization of medical care or social welfare.

In addition to this, while we cannot avoid pride-betting trade from caring, caring depends on carers' emotional sympathetic abilities. S hospital and nursing home's group-care practice does not necessarily entail this type of emotional sympathetic abilities on carers. S hospital and nursing home's group-care practice and the analytical framework from caregivers' structural cognitive arrangement would be suggestive of open caring to everybody.

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