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目次

はじめに

・・・・・・・・・・・・・・・・・・・・・・・・・・・・・・・・・・・・・・・・・・・・・・・・・・・ 5

日本のヘルス・プロモーションのポリシーについて—倫理学および政治哲学による批判的検討と今後の方向性に関する提言（大北全俊）

・・・・・・・・・・・・・・・・・・・・・・・・・・・・・・・・・・・・・・・・・・・・・・・・・・・ 7

持続可能な社会における予防原則（紀平知樹）

・・・・・・・・・・・・・・・・・・・・・・・・・・・・・・・・・・・・・・・・・・・・・・・・・・・ 45

Dialogue in Husserl’s phenomenology and psychiatry(Shinji Hamauzu)

・・・・・・・・・・・・・・・・・・・・・・・・・・・・・・・・・・・・・・・・・・・・・・・・・・・ 61

Intersubjectivity of Person-centred Care: a phenomenological perspective
（Shinji Hamauzu）

・・・・・・・・・・・・・・・・・・・・・・・・・・・・・・・・・・・・・・・・・・・・・・・・・・・ 71
Intersubjectivity of Person-centred Care:

a phenomenological perspective

Shinji Hamauzu

1 Opening Words: My background for today’s talk

My background is in philosophy, especially Husserl’s phenomenology of intersubjectivity. 20 years ago I published my dissertation titled “Husserl’s phenomenology of intersubjectivity”, and a few years later published the Japanese translation of Husserl’s Cartesian Meditations, then of the three volumes of Husserl’s Phenomenology of Intersubjectivity (Husserliana Vol.13 to 15).

For 15 years ago I have been also engaged with the problem of caring in a wide sense including stages from birth, ageing, disease and death. These four phenomena just mentioned are called the “four sufferings” by Buddha. However my interest doesn’t lie in the Buddhism, but in the contemporary situation around these phenomena which are totally changed especially after the World War II, partly because of the so-called medicalization.

With these interests in mind I met Karin Dahlberg in 2009 through the introduction of Marcia Schuback in Södertern University and took part in several meetings on “Caring and Phenomenology” or “Lifeworld-led-care” in Växjö University. Then I organized a interdisciplinary project “Philosophical background of Nordic Caring” supported by Karin with nine members for three years and now am organizing a second interdisciplinary project “Regional and Home Care in

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1 This paper was read on 22 September 2015 at Centre for Person-Centred Care (GPCC), University of Göteborg, organized by my friend, ex-professor Karin Dahlberg, and her friend, Inger Ekman, Professor of Care Sciences Sahlgrenska Academy, Centre Director GPCC, to both of whom I am deeply grateful.
Nordic countries” with nine members for three years which is now in the last year.

Last year in October, invited by Lisa Folkmarson Käll, I took part in the International conference at Centre for Dementia Research of Linköping University in Norrköping “Life with Dementia: Relations” and gave a talk titled “Dementia as a sickness of interpersonal relationship”. Today as it’s sequel I would like to talk with the title “Intersubjectivity of person-centered-care: a phenomenological perspective” by comparing the situation on dementia care in Japan with the situation in Sweden.

2 The present-day situation of ageing and dementia in Japan

According to WHO the rate of ageing of the population is defined as the rate of more than 65 years old person among the whole population. We call in Japan the society with more than 7 % of this ratio an ageing society, the society with more than 14 % an aged society, and the society with more than 21 % a super-aged society. Japan became an ageing society in 1970, an aged society in 1994 and a super-aged society in 2007. According to this definition we understand also that if the denominator decreases because of declining birth rate the rate of ageing of population increases even if the total number of aged people doesn’t increase. Therefore Japan is now a super-aged society with declining birth rate.

According to the “White Paper on Aged Society” in version of 2014 edited by the Cabinet Office of Japan, the whole population of Japan amounts to 127 million at the present of 1st October 2014 and the population of more than 65 years old amounts to 31.9 million. The rate of ageing of population amounts to 25.1 %, therefore more than one in four persons. In 2035, namely in the future about 20 years later, it is estimated that the rate will be 33.4%, namely one in three persons. In 2060 it is estimated that the rate of more than 75 years old people will amount to 26.9 %, one in four persons.

If we compare the rate of ageing of population in Japan with other European countries, Japan stayed in the middle in 1980s, came to the top of the world at the
beginning of 21st century and became a super-aged society which no country has experience. As to the speed of ageing the required time from 7% to more than 14% of the rate was 115 years in France, 85 years in Sweden, 47 years in UK and 40 years in Germany, whereas it was only 24 years in Japan.

Among the aged people also the number of people with dementia is growing every year. According to the statistic by the Japanese Ministry of Health, Labor and Welfare, the number of people with dementia amounts to 4.6 million in 2012 and it is 15% of the aged people. The half of them is estimated to be suffering from Alzheimer disease, 20% from Vascular dementia, 20% from Dementia of Lewy bodies. And if we count “Mild cognitive impairment” as a beginning step to dementia, it is estimated to amount 4 million, and if we count this MCI together with dementia, it is estimated to be totally 8.6 million, one among four aged persons. The problem of dementia is now a crucial one in Japan.

Dementia once used to be considered to be a phenomenon of ageing but now is diagnosed as a disease and an object of medical treatment. There are many different types of dementia, but the best course of action for treating dementia is not yet known. According to psychiatry, dementia has two different types of symptoms: core symptoms (disorders of memory, visual-spatial, language, attention, and executive function) and peripheral symptoms (behavioral and psychological symptoms of dementia: in short BPSD). The core symptoms could be treated medically though it is difficult, whereas the peripheral symptoms could be improved if they are cared well.

3 Medical Care for Dementia

According to the first article of the “National Guideline of Medicine and Caring for Dementia” (2010.5.1) of Sweden, “for the diagnosis of dementia, there must be an elementary investigation by a general doctor shouldering the primary care”. And as far as I’m informed, we must wait for six months until the doctor can diagnose as a dementia. It is a method that is recommended by ICD
(International Statistical Classification of Diseases and Related Health Problems) of WHO. The Swedish Guideline calls our attention to the fact that we must not simply rely on examination of machine such as brain imaging. This seems to be a totally different attitude of medicine to dementia from the one in Japan which follows DSM (Diagnostic and Statistical Manual of Mental Disorders) of APA (American Psychiatric Association) and doesn’t demand 6 months for it’s diagnosis.

According to the Japanese Ministry for Health, Labor and Welfare it is recommended to get a medical examination, diagnosis and treatment as early as possible. There are several types of dementia which are curable if they are diagnosed and treated in early stage. Otherwise they become incurable at later stage. Also for Alzheimer’s disease it is possible to hold up it’s progress. If it is treated in early stage, it make possible to live with health for longer period. But the diagnosis of dementia in an early stage is difficult and demands an advanced examination machine with a skilled technique. An examination at a special medical institution is indispensable. The Ministry recommends therefore that reliable relationships with a special doctor from an early stage are necessary.

People thought for long time that dementia is not a disease, but an inevitable symptom of ageing, and hence incurable. The development of medicine shows that we must distinguish between the symptoms of ageing and dementia as disease. However, dementia has a relatively short history, it seems to be a disease of the modern age and consequently, the method of treatment for dementia is not well established, at least not in Japan. Although the specialism of internal medicine and the psychiatry in Japan have a history of more than 100 years, it is only in last 20 years that dementia is medically understood and becomes an object of medical treatment. Now it is understood, that dementia is not a singular type of disease, but is instead a syndrome, ‘dementia’ is a name for a collection of symptoms and includes many types of diseases. Alzheimer’s disease is one of them, although the rate of it is more than the half of sufferers with dementia in Japan. Beside ATD (Alzheimer Type Dementia) there are other types of dementia
such as DLB (Dementia with Lewy Bodies), LPC (Lewy-Pick Complex), VD (Vascular Dementia), FTLD (Frontotemporal Dementia), etc. There are also some treatable dementia such as Chronic Subdural Hematoma and Normal-Pressure Hydrocephalus.

In such a situation, a Japanese Doctor, Kazuhiko Kono asserts that dementia is not incurable, it is only that many doctors don’t know how to cure dementia, although dementia must be differently treated according to the variety of it. He developed a new method called the “Kono-method” which is now in widespread use in Japan. It is primarily a method of pharmacotherapy. He insists that we need different courses of medication, depending on what type of dementia is diagnosed. If the doctor doesn’t know about such diversity of dementia prescribes an incorrect set of medicaments, then patients could fall in an unexpected situation from a side effect of the medicament. If patients with a different type of dementia from ATD get the famous medicament for ATD, called Aricept, then it could happen that they become much worse. Especially DLB have often been diagnosed as ATD for long time and prescribed with an incorrect set of medicament. The quantity of medicaments is important, too. In order that patients could take a correct set and quantity of medicaments, he leaves how to take medicaments to their family who know the everyday situation of the patient well. He prescribes not only western medicaments but also eastern, alternative medicaments.

Moreover Ko recommends a special supplement made from ferulic acid and garden angelica, called “Feru-guard”. This “Kono-method” seems to be a little suspicious, but is now adopted by more than 200 clinics or hospitals in Japan. Dr. Kono finds it false to think that person with dementia can do nothing and refers the book Who will I be when I die? (originally published in 1998, Japanese translation in 2003), written by a patient with dementia in Australia, namely Christine Boden, diagnosed as the early stage of ATD in 1995. But this requires a totally different approach to dementia beyond medical care including “Kono-method”.

75
4 Person-centered-Care

As mentioned above, various symptoms of dementia are distinguished into core symptoms and peripheral symptoms. The former are cognitive impairments such as memory loss, disorientation and so on, whereas the latter are other behavioral and psychological symptom of dementia (BPSD) such as delusion, hallucination, anxiety, wandering, aggression and so on. The former can mainly be treated by medical care, whereas the latter can’t in such a way, but are changeable, and could be made better or worse by depending on what care is given. If persons with dementia are cared for with dignity, humanity and respect, the peripheral symptoms could disappear. It means that they are not objectified by medicine, but their subjectivity is respected. This leads us from the medical model to the idea of person-centered-care established by Tom Kitwood in UK.

According to the third article of the above-mentioned Swedish “Guideline of Medicine and Caring for Dementia”, “all of medicine, nursing and caring should be based on person-centered-care and a teamwork of multi-professional cooperation”. Also in Japan, this idea of person-centered-care has been well known especially for care workers, since Tom Kitwood’s writings such as Dementia Reconsidered the person comes first (1997) or Person-Centered Care (2000) ed. by Sue Benson were translated into Japanese (both in 2005). Since then the Japanese Society of Person-Centered-Care was established and is giving mainly caregivers opportunities of a training or workshop of PCC in every big cities in Japan.

Nevertheless, the Japanese Ministry doesn’t seem to regard this idea as important when it comes to developing their policy because the concept announced by the Japanese Ministry in 2005 “A decade for getting to know dementia and making a region” intends to make a region where many supporters for dementia live and persons with dementia can live without anxiety. They don’t intend to enter into the subjectivity of persons with dementia. It seems to be
difficult that the idea of person-centered-care becomes a policy in Japan.

Apart from the Japanese government, the 20th international conference of Alzheimer’s Disease International (ADI) 2004 took place in Kyoto (Japan), it was reported that the interest in the person-centered-care in Japan is very high and that many people are educated of dementia care mapping (DCM). Another characteristic and noteworthy event of the same conference in Kyoto was that the above-mentioned Christine Boden was invited to a workshop and gave a speech, and that Japanese persons with dementia had an opportunity to stand on the platform and give a speech. The founder of person-centered-care, Tom Kidwood himself, didn’t about Christine Boden’s book, published just around his death in 1998. In his book Kidwood gives nevertheless seven approaches to get an insight to the subjective world of dementia, finds the first approach in the description which is written by a person with dementia in the period of having relatively little lost of the cognitive capacity and refers the book Living in the Labyrinth, written by Diana MacGowin 1993. If he had a chance to read the book of Christine Boden, he would estimate its value.

Before entering to the subjective world of dementia, I would like to mention the idea of “Humanitude” briefly, which was established by French physical therapists Yves Gineste and Rosette Maresotti and gained a lot of interest in Japan. Just last year it was introduced by a TV program and the Japanese book Introduction to Humanitude was published in June of last year. “Humanitude” is a method of recovering dignity and is composed of five techniques, namely of how to “see”, “talk”, “touch” and “stand”. In my opinion, however, they are techniques based on the idea of person-centered-care and are intending to neither change nor add anything to the idea of PCC, although it was sensationally introduced in Japan as a new method of caring for persons with dementia. I remember that many different ideas such as “validation” or “dignity therapy” are imported in Japan, but they have been soon forgotten as if they were a fashion. Now I would like to return back to the subjective world of dementia which was opened by the idea of PCC.
5 Person-Centred Research of Dementia from First Person Perspective

As I said, Christine Boden's book, Who will I be when I die? (Japanese translation in 2003), and her next book, Dancing with dementia (Japanese translation in 2004) were epoch-making also for those working in the caring profession and dementia in Japan. However, the idea that a person with dementia can have a rich original subjective world, has been developed originally also in Japan, without importing. For instance, a film of Sumiko Hada titled The world of elderly with dementia (1986) was a documentary about ordinary life of elderly with dementia, and another film titled Oriume (A broken ume tree, Japanese Apricot, 2001) described that a person with dementia keeps a creativity with feeling in paintings in spite of having lost memory.

Moreover, the Japanese psychiatrist Isao Ozawa published a book titled Living Dementia (2003), in which he described "How is the world from the perspective of elderly with dementia?", "What do they see, think and feel?" and "What kind of inconvenience do they live?", by quoting several Japanese novels and mentioning Christine Boden's book as a rarity, since it was a book written by a person with dementia. In his opinion, most of research on dementia so far was performed about dementia as a disease, or at best about how to care for elderly with dementia. They observed elderly with dementia as an object of their research or treatment. The intention to approach to how sufferers with dementia see their world and where their mind lies, and to accompany with them was very poor. There lacked an attitude to let them speak as a subject and to listen to them. He called the world of person with dementia as "lifeword", which stems originally from the founder of phenomenology, Edmund Husserl.

I have already mentioned that at the 20th international conference of Alzheimer's Disease International (ADI) 2004 in Kyoto (Japan), Christine Boden was invited to a workshop and also some Japanese with dementia had a chance
to give a talk in front of audience. The DIPEX international, which was founded to promote the spread worldwide of well researched data on people's personal experiences of illness and health at the University Oxford in UK, was introduce to Japan in 2001 and the DIPEX Japan was founded in 2007. This NPO (Nonprofit Organization) provides now many talks or narratives of person with dementia on the website.

Last year a Japanese TV program introduced an activity named as “Nothing about us without us” which was founded in Scotland. In this activity persons with dementia are working very active as subject. Moreover, in 2012 the Society of Person-Centred Research of Dementia from the first person perspective was founded. It intends to develop not only talks given by persons with dementia, but also researches of themselves, namely about what is their lifeworld, or how they see, think and feel the world. This idea of person-centred research stems in Japan from the regional activity of Bethel’s House in Urakawa town of Hokkaido, northern island of Japan, since 1984.

This activity was established as a community and cooperation of persons with mental disorders, mainly schizophrenia, and organized by a social worker Ikuyoshi Mukaiyachi. About six years later after the foundation as a cooperation of working for processing tangles, they began to research themselves from their first person perspective, for instance, about what kind of auditory hallucination or delusion they have, and to present their researches at first in their group as social skill training (SST), and then in front of audience. This activity of Bethel’s House brought many writings to the world, was introduced many times in TV program and became now very famous.

Recently books about Person-Centred Research, one by a person with cerebral palsy, another by a person with developmental disorder, Asperger syndrome, were published and this method of research by persons with various disabilities. Based on such a tendency, last year a book titled Investigation on the Person-centred Research (2013) was published, in which philosophical scholars discussed the philosophical meaning of the person-centred research from the first person
perspective. Moreover last year a Japanese translation titled Crazy in Japan – Ethnography of Bethel’s House from an English book was published.

The above-mentioned person-centred research of dementia could be settled among such a movement. However I would like to emphasize that also such person-centred research can not be performed only by the first person perspective, but by the interaction of the first and the second person perspective, namely interpersonal relationship. The person-centred research of Bethel’s House was characterized by its founder Mukaiyachi as “By myself, and Together”. “By myself” means that researches of mental disorders should not be left in doctor’s hands, but performed by oneself, whereas “and Together” means that such person-centred research could be however only be possible through self-help activity with a supporter or in group, namely through interpersonal relationship.

6 Intersubjectivity of Person-centered-care and Lifeworld-led-care

As mentioned above, the peripheral symptoms of dementia could disappear if persons with dementia are cared for with dignity, humanity and respect. It means that dementia is no disease which happens only to an individual, but has especially in its peripheral symptom a character of sickness of interpersonal relationship. Although the person-centered-care seems to be caring for an individual by emphasizing the subjectivity of person with dementia, even the founder of PCC Kitwood emphasized in term of “intersubjectivity” that the most important task is the improvement of quality of interaction. The idea of PCC could be considered to be in a sense a part of paradigm change from paternalism to informed consent. But the problem is how we should understand the word “person”. If we understand with it a subject with intellect, mental capacity and self-determination, we could not grasp the problem of dementia well. The person-centered-care should be understood with intersubjectivity. This means just that the person-centered care can change peripheral symptoms of person with dementia. The idea of PCC
should not be individualized, but understood as an example of intersubjectively.

Intersubjectivity as a phenomena is always found within a wide context of the above-mentioned “lifeworld”, which is mainly composed of “temporality”, “spatiality” and “intersubjectivity” in a different sense from scientific understanding. Persons with dementia live in a lifeworld with original temporality, spatiality and intersubjectivity. The person-centered care leads thus to the “lifeworld-led-care” which I learned from a Swedish scholar, Karin Dahlberg. It will attempt to understand what kind of lifeworld the sufferer is dwelling. With this idea not caring at institutions that is broken off from lifeworld, but caring at home in a regional lifeworld is reconsidered now.

According to the seventh article of the Swedish Guideline of Medicine and Caring for Dementia, “a commune must endeavor so that persons with dementia can dwell in a small-scale, equipped for individual patient, familiar and plentiful special house”. This idea can be understood as a variation of “lifeworld-led-care”. Comparing with the Swedish guideline, I find the above-mentioned plan of Japanese Ministry poor, which intends to make a region where many supporters for dementia live and persons with dementia can live without anxiety.

7 Closing Words

Before I come to Göteborg I spent a week in Helsinki in order to give two talks: the one titled “Dialogue in Husserl’s phenomenology and psychiatry” was read at an interdisciplinary workshop “DIALOGUE AND INTERSUBJECTIVITY” with which the main figure for the new movement “Open Dialogue”, namely Jaakko Seikkula (University of Jyväskylä) took part; the second titled “Intersubjectivity of Ageing - Reading Beauvoir’s The Coming of Age” was read at the seminar for philosophy.

At closing words I would like to mention the new movement of mental health from Finland which is introduced recently in Japan and which we can find a sympathizing idea of “meeting” of the Bethel’s House. It is called “Open
Dialogue” which I mentioned above. This method is practically inherited as one method to treatment intervention for patients with schizophrenia, centered in family therapists of Keropudas Hospital in Tornio, west Lappland Finland since 1980s. A team of experts should visit clients in critical situation of acute stage within 24 hours after request and open a dialogue everyday among patients, family and relatives until the situation would improve. This method doesn’t use any medicament, but heal only through conversations. They discuss with all together a method of treatment, a possible pharmaceutical treatment and the pros and cons of hospitalization. They must not decide anything without the person concerned: it is the rule. They say: “In an ambiguous situation just a dialogue gives us a hope and a clue to get out of labyrinth”.

These cases of “meeting” of Bethel’s House in Japan and “Open Dialogue” in Finland we can find that people practices even against the common knowledge of mental medicine in order that the person concerned can recover talking.

Although Japan is now standing at the frontline because of the highest rate of elderly among the whole population in the world, the idea of caring for persons with dementia in Japan is still in developing level. We can learn much more ideas from Nordic countries especially from Finland and Sweden.