Self Study Meeting—An alternative care for Medication by Bethel’s House in Hokkaido—

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ABSTRACT
This research explores the possibility of communication-based care as an alternative to medication, especially when the disease in question appears incurable, with the aim of suggesting more appropriate ways of communication in Medicine and Care. Previously, communication problems in Medicine were considered to occur just between doctors and patients, for example concerning informed consent, with the result that research so far has focused on problems in the transmission of technical information between experts targeting a specific fixed treatment outcome, and laymen just searching for improvement of their condition. Another difficult issue in Care is the asymmetrical relationship between the giver and the receiver of care. In this paper, I suggest approach to interaction in Medicine and Care, designed to help patients lead a satisfactory life, and providing a new point of view on the socialization of care.

Keywords: Bethel’s house, Care, Communication

INTRODUCTION
About 353,000 people with mental disorders are hospitalized in Japan. Also Japan has the highest number of beds in mental hospitals as a ratio of the total population. Currently, treatment is primarily pharmacological. However, some of the mental disorders like schizophrenia cannot fully be cured with medication at present and require life-long care. Although the promotion of socialization of care is emphasized in Japan and in 2000 a national nursing care insurance system has been implemented, care inherently has a certain something that cannot be socialized. This “something” seems to derive from the uniqueness of each individual life, death and “disease,” and from the wish to be treated as “irreplaceable being”. The alternative
communication-based treatment discussed here aims to attend to the uniqueness of each person and her/his sense of self as an irreplaceable being.

I employ a Narrative Approach to examine Communication-based treatments, and to elucidate what makes it unique. I argue that a human being is irreplaceable not only because of its biological life and its capability for self-consciousness, but also because of its “narrative of the self”. People each live a unique life and narrate about it, and these narratives create their identities. The narrative of the self develops in interaction with others. Human dignity is derived from the personal narrative through open-ended interactions within the symmetrical relations that constitute the individual’s intimate sphere.

This consideration opens up a wider perspective on the question of what “Care” and “Health” are. The focus of this exploration is Bethel’s house, a care home in Urakawa (Hokkaido, Japan) as an example of communication-based treatment which is unique and fresh in Japan. It is named “Self Study Meeting”.

**MAIN CONTENT**

**Quality of Life and Problems**

Quality of life has been emphasized in Medicine and Care. According to Joseph Fletcher, “the traditional ethics based on the sanctity of life—which was the classic doctrine of medical idealism in its prescientific phases—must give way to a code of ethics of the quality of life. This comes about for human reasons (Fletcher 1973)”. However, I have felt discomfort with the term “quality of life” for a long time. Because in referring to quality of life, this quality is treated as something measurable against other qualities; quality is quantified. Fletcher also writes, in “Ethics and Euthanasia”:

*Let’s say it again, clearly, for the sake of truly serious ethical discourse. Many of us look upon living and dying as we do upon health and medical care, as person-centered. This is not a solely or basically biological understanding of what it means to be “alive” and to be “dead.” It asserts that a so-called “vegetable,” the brain-damaged victim of an auto accident or a microcephalic newborn or a case of massive neurologic deficit and lost cerebral capacity, who nevertheless goes on breathing and whose midbrain or brain stem continues to support spontaneous organ functions, is in such a situation no longer a human being, no longer a person, no longer really alive. It is personal function that counts, not biological function. Humanness is understood as primarily rational, not physiological (Fletcher 1973 p.671).*
According to Fletcher’s “doctrine of man”, to be human requires to be “more valuable than being alive”, and it places that value in man’s “ratio”, i.e. reason (Fletcher 1973). This is continuous with John Locke’s definition of personhood in An Essay Concerning Human Understanding (Locke 1690), in which he states reason, the ability to reflect, and intellectual existence with self-consciousness as requisites. Similarly, Michael Tooly writes in 1972:

An organism possesses a serious right to life only if it possesses the concept of a self as a continuing subject of experiences and other mental states, and believes that it is itself such a continuing entity (Tooly 1972 p.44).

Human fetuses and infants do not satisfy his condition and consequently do not “have a serious right to life (Tooly 1972)”. To modify Tooly’s radical theory, H. Tristram Engelhardt suggests we distinguish two kinds of “person” in 1982. He basically defines personhood in terms of reason and a sense of self-consciousness, but he also proposes a social personhood for those that are not persons under the first definition but nonetheless are treated as persons within society, for example infants, developmentally disabled people and people with serious mental disorders (Engelhardt 1982). In accordance with the previous utilitarian approach, Peter Singer proposes a more clear-cut line between person and non-person in Practical Ethics in 1979. He rejected the human-centered ideology of personhood and suggests as a new criterion for personhood: the capability to feel pain. This criterion leads to inclusion of other animals and exclusion of some human beings (Singer 1979). Singer states that some life cannot enjoy any kind of pleasure or cannot have even low level of self-consciousness. Those lives are not worth living. Some newborn lives that are bound to be painful (due to for example spina bifida) are not worth living. If there are no counter-factors (like e.g. the parents’ wishes) then those lives should be canceled. Thus Singer justified the euthanasia of infants with heavy disabilities. Singer suggests that in terms of quality, some lives are superior or inferior to other lives, and those lives that are superior in quality should take precedence (Singer 1979).

I follow Fletcher insofar that “being human is more valuable than (merely) being alive”. However I do not put “the homo and ratio before the vita”. Even if the conditions for personhood (a brain or central nervous system enabling continuous self-consciousness, reasonability or the capability to feel pain) are met, still a big question remains: Who can judge one’s life miserable or not worth-living besides the one who actually lives that life?

I put the homo and the narratio before the vita. Masayoshi Morioka and Tomoko
Yamamoto who employ the Narrative Approach as a care method, state that humans can create or even recreate reality and even themselves through words (Morioka, Yamamoto 2013). Based on the Narrative Approach, there is an ontological idea of Human as organizing reality and creating meaning by picking up material from the reality of life, fitting it into the contexts generated there, and putting it into words. This process is called “Narrative” (Morioka, Yamamoto 2013). Narrative has a social performativity and depends on others’ responses to positively create a dialogue. The interaction of narrator and listener is cooperative and symmetrical. I hold that Humans derive their irreplaceable dignity from the process of living and creating their own narratives through their dialogues with others. When we consider the quality of a life in terms of its narrative, it cannot be relative or comparative to other qualities of lives. The quality of any given life is something absolute; it can only be measured within the context of that life’s own narrative.

**Bethel’s house and Self Study Meeting**

Bethel’s house is located in Urakawa, a small town with a population of 14,000 in a southern part of Hokkaido. The house was originally founded in 1978, by patients that had been discharged from the psychiatry department in the Urakawa branch of Japan Red Cross Hospital. Initially they formed a mutual support group named the “Acorn Club”. They started to live together in an old abandoned church next to the hospital and the pastor who was supporting them named the ex-church “Bethel’s House” in 1984. The people living there put much emphasis on meetings as attested by their motto: “Meeting first, meal second”. Bethel’s house is famous for a meeting known as the “Self Study Meeting”.

Michio Saito, a journalist who has interviewed the members of Bethel’s house, and presents their stories in his book *Naorimasen you ni—Bethel’s house no ima—*(Don’t let it be cured —Bethel’s house Now —). Firstly I will introduce two cases of members with schizophrenia and then use those cases to illustrate the Self Study Meeting and its effects.

Mai Suzuki came to Bethel’s house when she was 24, suffering from terrible auditory hallucinations telling her to kill herself. She was hospitalized 6 times, and was prescribed large amounts of pills that kept her in a haze. She insisted on wanting to die if she was kept in that haze forever. She was born and raised in Aichi prefecture. When she was in the 1st grade of high school, she started to feel depressed and became socially withdrawn. After she graduated from high school and moved to Tokyo to study at a technical college, she started to suffer from auditory hallucinations, with 5 different personalities, saying things like: “You’d better kill yourself”, “You’re not worth living” and “We’re both going to die together”. She quit...
school and returned to her hometown but her condition would not get better. She suffered from sleeplessness, wrist cutting, and thought broadcasting: the feeling that the others could read her mind. When the condition worsened, she was taken to the emergency room. However, the amount of pills merely increased and the condition became progressively worse. Finally she came to Bethel’s house in fall of her 24th. At Bethel’s house, no matter how often she would claim that she wanted to die, no pills would be prescribed. Instead, the people there would ask her, with smiles on their faces, about the reason why she felt that way, and repeat maxims she could not understand, like: “My disease is my treasure” and “Do not cure my sickness without my permission”. Even the social worker said “I don’t understand you if you just say you want to die. You’re at Bethel’s house now, so you have to speak in our language”. Initially she was quite confused but she gradually came to understand that she could freely express her feeling that she wanted to die. Before, whenever she said so she was taken to the emergency room and that meant denial of the feeling. However, at Bethel’s house any kind of feeling is accepted, but patients are required to explain the reasons behind their feelings. Eventually she realized that by saying she wanted to die, she was actually expressing her deep and profound desire to live. She came to learn this method, known at Bethel’s house as “Urakawa language”. Another well-known method is that of personally addressing Gencho-san (“Ms./Mr. auditory hallucination”): naming one’s auditory hallucinations and treating them as personalities, with the aim to treating them attentively and get along well with them. At Bethel’s house, all the members refer to auditory hallucination as Gencho-san. Auditory hallucination appears in 60~70% of people with schizophrenia. It hurts and confuses the patients with negative instructions and sentiments like “you’d better kill yourself” or “you are stupid”. Some patients take such orders and jump out of a window or try to kill themselves otherwise. In psychiatry, auditory hallucination is traditionally seen as something that should be negated. In order to annihilate it, strong medication is prescribed in large doses, and this puts patients in a haze where they can barely move or think on their own. People at Bethel’s house came up with another method that aims for peaceful coexistence with one’s auditory hallucinations. In the 1990s, some members rode it on the snaffle by asking “Please stay calm today, Gencho-san”, which worked well in many cases at Bethel’s house. Members tenderly observed Gencho-san growing up and this approach became widespread even outside the house. Of course, with this approach the auditory hallucinations do not disappear, but it offers temporary relief from their hostility. The method is not necessarily effective for everyone, but its discovery was quite surprising to the members, and since then, they have decided to call auditory hallucination Gencho-san, treating even the aggressive ones with respect, while trying to raise them into gentle ones.
Another famous approach is that of “Okyaku-san”, “the Guests”. The Guests are the members’ intrusive negative thoughts. Sometimes, a member may come to think that the other members must hate her/him. That is a case of “being visited by a Guest”. Other examples given are the thought that one is useless, or the delusion that others are casting stones at them. It is in many regards similar to auditory hallucinations, but different in the sense that Guests are thoughts instead of sounds or words like Gencho-san.

Sonoko Hayashi is from Nagoya suffering from the obsessive checking behaviors. For example, when the meeting is planned to starts at 3 o’clock, she cannot help making sure repeatedly 20-30times about the time. It is very afflictive to herself and the people around her. She tried to figure out the conditions under which those obsessive behaviors occurred. She analyzed that it occurred when she was worried (Nayandeiru), tired (Tsukareteiru), had time and nothing to do (Himade), lonely (Sabishii), had no money (Okaneganai) and hungry (Onakagasuita). Then she shortened the conditions into Natsuhisao gathering the initials of each condition and made a cute mascot. She had a great sense of humor. Her obsessive behaviors kept on annoying many other members, but those behaviors were gradually accepted by the other members as burdens which should be shared with her stories (Saito 2010). She states as follows;

When I was in Nagoya, I was totally obsessed with my sickness, 99% of my life. But after I came here (Bethel’s house), everyone led me out to the outer world. Now I am happy. I have become happy (Saito 2010).

She also states that previously, it was the problem of frequency of injection or the amount of the pills. She states that care at Bethel’s house has changed the physiological problems (She describes as animalistic problems) into personal problems (Saito 2010). With all the pain and joy she gets from her sickness, she has got her sickness back in her hand.

**Effects of Self Study Meeting**

I suggest that Self Study Meeting involves not only the externalization and objectification of one’s syndrome but also the following factors; Separating “the Guests” from the members themselves, naming them, and treating them as if they have personalities (which in fact they do). Then members try to comprehend “the Guest’s” condition, by tracking for example under what circumstances their conditions get better or worse, and then Care for them. Furthermore, in expressions like “I don’t want to be cured” or “Don’t cure me without my permission” one can see
that the members accept their “Guests” as partners in their lives. This process turns these people, having been care-receivers for a long time, into care-takers, as they take care of their Guests. These processes are openly shared, in order to help other members learn to care for their guests. Thus in the relations between the members too, we see a process of switching from care-receiving to care-taking. Nel Noddings suggests the traditionally asymmetrical relation between care-taker and care-receiver is in need of restructuring into a mutual and bilateral one (Noddings 1984). I suggest that mutual and bilateral relationships have realized among members and their syndromes. Also, Junnichi Saito defines intimacy and says that it is the relationship based on care for the specific other especially for its difficulties (Saito 2003). I suppose that at Self Study Meeting, among members and members’ syndromes, some kind of symmetrical intimate sphere is generated and that generation overcomes the problem of asymmetrical relationship in Care. In addition, care at Bethel’s house that is based on the intimacy but not on the kinship proposes the possibility of socialization of care. Haruki Miyoshi, Physiotherapist and philosopher promotes the socialization of care in town or block level (Miyoshi 2005). Bethel’s house casts a new perspective on creating an intimacy sphere not in geographic terms but by the narratives as interaction.

CONCLUSION

What is the Quality?

Hiroto Takenaka, a member of Bethel’s house suddenly died in May 7th 2004. He was 28 years old then and was stabbed with knife into his stomach by another patient of Urakawa Red Cross Hospital. The assailant was suffered by persecution complex of being killed by Mr. Takenaka. His death poses a fundamental question about what values to pursue in Care and Medicine.

After the tragedy, severe criticism arouse against Bethel’s house, Urakawa Red Cross Hospital about their Security provision although Takanaka’s parents invite the assailant’s family to the funereal to show their sympathy. Sonoko Hayashi also passed away because of heart disease in 2004. Her disease was caused by one of her obsessional behaviors, drinking 4 or 5 liters of water a day (Saito 2010). You may say that those two deaths are due to the care at Bethel’s house that puts much emphasis on meetings, tries to coexist with the diseases, refrains from much medication and tries not to control the members. Mr. Takenaka and Ms. Hayashi decided to come to Bethel’s house in search of the care, “not to kill the emotions with medicine”, “not to be controlled” but “respect the sanctity of life” and to choose “something that cannot surrender” (Saito 2010). If they were in Medication-centered and controlled hospital, they might have lived longer. However, they did not want that kind of lives. Saito
states about the tragedy as follows:

If the human life (biological life) is the supreme value and superior to any other values, there is nothing to pursue beyond Individuals life (biological). However, there is a value that people at Bethel’s house have pursued spending extremely long time and with millions of meetings and that is something they cannot surrender (....). If there is a place constructed where things like Mr. Takenaka’s tragedy would never happen, they cannot survive in that kind of place. That is not based on reason or opinion but based on the absurdness that their lives require (Saito 2010).

Sonoko Hayashi says to Dr. Kawamura, a doctor at Urakawa Red Cross Hospital.

I don’t want to cure my sickness anymore. I do hear the auditory hallucination. Sometimes, my mind is filled with persecution complex. But I don’t want my sickness to disappear. I would feel so confused if I lost it (Saito 2010).

Both Mr. Takenaka and Ms. Hayashi had created their own narratives with other members and syndromes at Bethel’s house, and then died. Was that because they valued those narratives as something precious? Those irreplaceable narratives are the main part of Quality of Life in Medicine and Care and that quality of any given life is something absolute and can only be measured within one’s own narrative. Previous conditions for personhood, a brain or central nervous system enabling continuous self-consciousness, reasonability or the capability to feel the pain are relative to each other and can be measured in quantity. We have to pursue to respect the Quality of life as unique narratives and also the creative interaction as the foundation of those narratives.

REFERENCES


Miyoshi, Haruki. & Kawamoto, Takashi (Eds.).(2005). Care in the block and Eros (Kaigo no chounaika to Eros wo) *Social Ethics and Care —Connecting Medicine, Nursing, Care and Education*. Tokyo: Yuuhikaku

Morioka, Masayoshi. & Yamamoto, Tomoko.( 2013). Employment of Narrative
Approach in Psychological Interaction Assistance and Narrative as creation. 


Saito, Michio. (2010). *Naorimasen you ni —Bethel’s house no ima —(Don’t let it be cured —Bethel’s house Now —)*. Tokyo: Misuzu-syobou
