

# The Meaning of Self-presenting as a ‘Cyborg’

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## 1. The cyborg

There are some people who use technology as part of their bodies and self-present as “cyborgs”. In this paper I consider, through examining the case of a woman who received an OOKP transplant, the connotations of references to “cyborg” when used in self presentation.

“Cyborg” is a word that was created by Manfred Clynes and Nathan Kline by combining the words “cybernetics” and “organism”. Human beings cannot survive in outer space, and Clynes and Kline originally conceived of “cyborgs” as astronauts who attached biological feedback devices to their bodies in order to maintain homeostasis and thereby survive in what would otherwise be a lethal environment (Clynes & Kline 1960 ).

Danna Haraway sees the idea of the cyborg as a combination (hybrid) of a living creature and a machine and uses this a metaphor for the violation of boundaries which has been one of the goals of the western scientific tradition. This tradition has struggled to overcome the boundaries built by the dichotomies of self and other, mind and body, culture and nature, man and woman, and creator and created. Haraway points to three boundaries being destroyed in the high-tech culture of the latter half of the twentieth century: the border between humans and animals, the border between living creatures (humans and animals) and machines, and the border between the physical and the non-physical. He maintains that the ontological distinction between machines and living creatures has already disappeared (Haraway 1991).

Sankai Yoshiyuki has developed the Hybrid Assistive Limb (HAL) which is categorized as a “robot suit” or “power assisted suit”. According to Sankai, the term “Hybrid Assistive Limb” refers to various aspects of hybridization: human and robot, voluntary and autonomous, muscle and motor. Sankai does not view HALs as cyborgs; he created the new concept of what he calls “cybernetics” and within cybernetics he places HALs in the sub-category of what he calls “cybernetoids” (Sankai and Matsubara 2008).

Focusing mainly on Brain-Machine Interfaces (BMIs), Mima Tatsuya has pointed out a shift in the direction of the pursuit of cyborg technologies. While Clynes and Kline conceived of cyborgs as means of traveling through outer space, today's cyborgs explore what might be called “inner space” as a tool of human understanding. When cyborg technology is used to provide support rather than treatment, it seems that the people with disabilities who are willing to mechanize their legs or arms tend to be those who are already able to live independently by using caregivers as tools (i.e., as their own arms and legs). Mima sees in this the negative aspect of incentives toward independent living, behind which he sees the strong self as an anglo-saxon subject and the division of labor in modern societies where human beings are used as tools. He asserts that the use of technology to facilitate communication and

allow people in a “locked-in state” to express themselves is more important than this kind of physical/material attainment (Matsubara and Mima 2008).

In the points made by Sankai and Mima outlined above we can see both expectations and concerns surrounding enhanced ability and the bright future in which such enhancements are possible. On the contrary, people who have used this kind of technology on their own bodies or observed this use closely talk about cyborgs from a different point of view. In writing about this issue Morioka relates the feelings of the mother of a woman he knew who had entered a state of brain death. When she sees her daughter attached to various tubes and monitors, Morioka quotes her as saying “I feel like she is somehow losing her humanness and becoming more like a cyborg or material thing” (Morioka 2001:12 [translated from the Japanese]).

Kitamura Kentaro quotes a patient with hemophilia as saying “we are cyborgs after all”. According to Kitamura, the greatest suffering experienced by hemophiliacs is caused by bleeding inside joints and muscles which inflicts excruciating pain until it can be stopped. Hemophiliacs receive the coagulating agents their body cannot produce through a technique called “home infusion”. Kitamura refers to the self presentation quoted above in classifying hemophiliacs who rely on “home infusions” to enable them to live their lives as “rechargeable cyborgs” (Kitamura 2009).

Tateiwa Shyn'ya has focused on the inconvenience and discomfort that arises surrounding the joining of body and machine by looking at statements made by groups of people with cerebral palsy and cases in which ALS (amyotrophic lateral sclerosis) patients have been put on ventilators. He states that while on the one hand treatment should be carried out if recovery can easily be achieved, disabled people's groups do not always view treatment as worthwhile. These groups have pointed to the “payment” required to receive treatment, including not only the obvious financial costs but also the time and restrictions on their lifestyle required until recovery can be achieved and the additional suffering they must endure. In cases where a cure is impossible or its costs would outweigh its benefits, the option of compensating with the assistance of caregivers or machines rather than pursuing treatment arises. It goes without saying that here too suffering should be minimized. The most important problems related to the use of machines are thus not abstract questions about the violation of boundaries but practical issues such as the pain and discomfort caused at the places where machines are connected to the body and the fact that these issues are not sufficiently understood and addressed. Regarding situations in which a severely ill patient is surrounded by machines that make them look like a “cyborg” to other people, Tateiwa maintains that while some machines may be unnecessary there are those which cannot be done without, and therefore opposes the use of abstract or negative statements such as “a state of being just connected to machines” and “spaghetti syndrome” (Tateiwa 2008).

In conducting an interview survey of patients with SJS I encountered a respondent who uses a representation of “cyborg” in self presentation. In this paper I will refer to this respondent as “Ms Tachibana”. In the interview survey and her letters and emails Ms Tachibana self presented using the term “Mekuraian”. “Mekura” is a derogatory Japanese term for “blind person”. When I asked Ms Tachibana during the interview why she had added “ian” to “mekura”, she replied that she was a “cyborg” because she had recovered her vision

through an operation in which a tooth had been transplanted into her eye, and that in Japanese manga cyborg characters often have names that end in “ian”.

Based on the results of the interview survey conducted with Ms Tachibana, in this paper I will examine self presentation as a “Mekuraian”, a representation of cyborg, from the point of view of the positive and negative results of the use of technology.

## 2. Osteo-odonto-keratoprosthesis (OOKP)

As I will discuss in part 3, Ms Tachibana, the patient whose case is examined in this paper, became nearly blind as a result of SJS (Stevens-Johnson syndrome) [1] and then recovered nearly “normal” vision by receiving an OOKP transplant. Of the four people who have received an OOKP transplant in Japan, three had lost their sight as a result of SJS and two of these are members of the Japan SJS Foundation. Before turning to the case of Ms Tachibana I will first give a brief explanation of the procedure she underwent, a transplant technique developed in Italy and referred to as OOKP.

The use of corneal transplants to treat the corneal opacity that arises as an aftereffect of SJS is contraindicated because of its low success rate. As it is difficult to restore a patient's vision through medication/eye-drops, there has been a need for the development of a surgical procedure which would be effective in these cases, and in recent years several different methods have been tried. Broadly speaking surgical approaches to restoring visual function in patients with corneal disease can be divided into two basic approaches. One involves regenerative treatment. Techniques such as transplanting a corneal surface cultivated using corneal surface stem cells or transplanting an oral membrane grown using oral membrane cells have already been developed and applied clinically. The other approach involves artificial corneas. Artificial corneas (keratoprosthesis) are transparent objects made of materials like poly methyl methacrylate (PMMA) that are inserted in place of clouded corneas (Sotozone 2000; Nakamura and Kinoshita 2002). The OOKP procedure discussed in this paper is one form of this latter approach.

Approaches connected to today's artificial corneas have a history of over two hundred years. An artificial cornea was first implanted into a human body by Nussbaum in 1855 and was made of quartz. From that time until around 1900 various different artificial corneas were implanted but in almost all cases failed to remain in place. In the 1950s corneal transplants became more common and for a time less attention was paid to artificial corneas. However, the use of artificial corneas was later revived as a means of addressing cases in which corneal transplants were not successful. In Japan pioneering efforts were made in this field in the 1890s, but this early experimentation did not continue into the twentieth century and the development of artificial corneas was for the time being aborted. This development began again in the 1970s, but in general the long-term prognosis of this procedure remained poor. In 1963 an Italian researcher named Strampelli announced the development of an artificial cornea in which the optical section was fixed in place using pieces of tooth and bone. Attempts to replicate his results were carried out around the same time in the U.K., however, and in almost all cases the artificial corneas fell out. Falcinelli obtained good results when he

improved Strampelli's method by resecting the iris, crystalline lens, and the frontal portion of the vitreous body of the eye when implanting the artificial cornea on the surface of the eye. This OOKP procedure continued to be used in Italy, Austria and Germany, and in 1996 was introduced in the U.K. by Liu Christopher and Herold Jim. With the intention of introducing OOKP in Japan, Lui, Fukuda et al. reported that that there had been 573 cases in which the procedure had been performed up to that time, with the longest observation period being twenty-seven years (Liu, Fukuda, Kinoshita and Hamada 2002; Fukuda, Liu, Hamada and Kitamura 2003; Fukuda 2004; 2005; Uemura 2008 ).

OOKP implantation involves two surgical procedures with a two to four month interval between them. In the first operation the patient is given a general anesthetic and the following two procedures are performed:

A. The surface of the eye is reconstructed

B. The osteo-odonto-lamina holding the optical component is embedded in the orbicularis muscle of the eye.

Procedure A begins with a piece of mouth mucosa roughly 3cm in diameter being removed from the oral cavity. The surface layer of the eye is removed and the mucus membrane is attached in its place to create a new surface. In procedure B a canine tooth (including the root) is extracted and shaped with a drill to form an "osteo-odonto-lamina" in which one side is composed of the root of the tooth and the other side is a thin section of bone. A hole 3mm-4mm in diameter is drilled in this osteo-odonto-lamina and a cylindrical optical component made from PMMA is fixed inside it using dental adhesive. Canine teeth are used because a large tooth with a single root is needed in order to insert the optical component. This structure is then embedded in the orbicularis oculi muscle below the eye which is not being operated on. There is an interval of two to four months between this operation and the second operation to allow time for granulation tissue to grow around the osteo-odonto-lamina and blood vessels to grow into the membrane which has been transplanted onto the surface of the eye.

For the second operation the patient is again put under a general anesthetic. First the osteo-odonto-lamina that had been implanted in the orbicularis oculi muscle in the first operation is removed. The granular tissue that has grown around the the tooth side that will face towards the cornea is removed, and excess tissue is removed from the bone side leaving only a small amount remaining. A "U" shaped flap slightly larger in diameter than the cornea is cut in the membrane that had been attached to the surface of the eye and the lower portion of the flap is lifted up. The center of the exposed cornea is marked and a hole 3mm-4mm in diameter is made. In order to prevent post-operative inflammation and the formation of a membrane over the back of the optical component, the iris, crystalline humor and anterior hyaloids body are removed from the eye. The optical component of the osteo-odonto-lamina is inserted into the opening in the cornea and the lamina is attached to the surrounding surface of the eye. After suturing has been completed a hole is cut in the membrane flap to allow the optical component to protrude once it has been put in place.

### 3. Pros and cons of recovering vision with OOKP

I have published three papers about the case of the OOKP recipient I have been referring to as “Ms Tachibana” (Uemura 2007a, 2007b, 2007c). This section is based on what was reported in these papers.

Table one organizes Ms Tachibana's evaluation of the changes brought about by the OOKP transplant when comparing her situation before and after undergoing the procedure in terms of positive and negative results. Two other tables have been created in order to make clear the circumstances which led Ms Tachibana to give this kind of evaluation. Table two shows the explanations Ms Tachibana received from her doctor as part of obtaining her informed consent and her understanding of them. Table three is a timeline of important events in the life of Ms Tachibana from birth until the present time.

**Table 1. Positive and negative results of recovering vision with OOKP**

<b>Positive Results</b>
<ul style="list-style-type: none"> <li>• She had not thought that she would ever regain her vision, so she will never forget the first time she was able to see again.</li> <li>• She went outside and travelled.</li> </ul> <p>“In the market, for example. There are vegetables I have known all my life. Now I just stare at them. ‘Wow!’ I say to myself. ‘Is that what they look like?’ I look again. I stare at everything as if I were filling in the blank spaces of the past five years. Even when I am looking at completely ordinary things, that ordinariness is special for me. When I look at the stars I just can’t believe it. I keep thinking ‘I can see the stars!’.”</p> <p>“I had gone through a period of not being able to see, so just looking at things again make me happy. I realized how big a loss it had been. ”</p>
<b>Negative Results</b>
<ul style="list-style-type: none"> <li>• <b>Regarding visual function</b></li> </ul> <p>Her field of view is narrow.                      When looking towards a bright area, light expands like a halo in front of her eyes.                      She cannot see in dim lighting and when there is enough light for her to see it feels too bright.                      She has to use two pairs of glasses, one for objects far away and another for objects close by.                      While her visual acuity is said to be stable, the large amount of eye-mucus and high ocular tension she experiences means that in practice she feels her vision is far from stable.                      She cannot close her eyelids.                      When she blinks the sensation is strange and it feels like she is winking. Her right eye has a tendency to drift downwards.</p>

• **Regarding daily maintenance**

She must not let water get in her eyes, so she cannot wash her face and must bathe with care.

She must put ointment in her eyes and cover them before she goes to sleep and as a result cannot just fall asleep when she feels like it.

She must wipe off the ointment in the morning.

If she does not put on ointment, she feels pain caused by the transplanted oral membrane and her eyelids rubbing against each other. When the ointment applied to the edge of her eye melts and drips over the lens she cannot see.

When she sweats the ointment tends to run down from the edge of her eye so she avoids moving and does not go outside in summer.

She had been more active before regaining her sight.

She always has to be careful because she cannot have a second operation if she damages her eye by bumping into something.

In order to lessen the impact if she were to bump into something she wears a sun visor at all times.

• **Regarding appearance**

Her face looks much older.

Her eyes do not move and cannot express emotion. She is not in a condition to discuss the beauty or ugliness of her face. She does not wear lipstick or foundation because she cannot wash her face and does not want to smear makeup on people she bumps into.

Because she is a woman it bothers her that she cannot wear makeup. Recently she has gotten used to her own appearance, but she finds the way she looks disgusting and hates seeing her own face.

• **Regarding dentistry**

The false tooth implanted in place of her canine tooth accumulates tartar and plaque. The place where her membrane was removed is still numb and sometimes she drools without realizing it.

• **Regarding communication with others**

Because of the various problems discussed above it is unpleasant for her when people say things like "it's great that you can see again" or "you can see better than I can!".

She worries about whether people will be put off by looking at her, tends to keep her eyes pointed downwards and does not like being face to face with another person.

She wears dark sunglasses in order to prevent other people from seeing her eyes, but in some cases the lighting conditions allow them to be seen nevertheless.

• **Regarding the social security system**

As a result of recovering her sight she was cut off from receiving funds for victims of the harmful side effects of medicines.

Her grade of disability pension dropped from 1st to 3rd.

She is frustrated by the fact that these changes occurred just because of a visual acuity score measured with a standard eyesight test.

**Table 2. Explanations Ms Tachibana received before her operation and her thoughts about what she was told.**

<b>Explanation Received</b>		<b>Thoughts</b>
Your eye(s) will be pink.		If the operation fails I won't be able to see and I will have turned my eye pink for no reason. But my eyes are already white, so it wouldn't really make any difference if they turned pink.
Your field of vision will be narrow.		It did not mean very much to me.
You will not be able to close your eyes or blink.		It did not mean very much to me.
Your Irises will be removed.		It did not mean very much to me.
Your tooth will be extracted from its root, and a lens will be inserted into it.		It did not mean very much to me.
Your canine teeth have decayed and there is only one remaining that could be used in this procedure.		I have to have the operation while I still have a useable tooth. I have to have the operation right away.
I recall being told my vision would probably be around 0.7 or 0.8.		
The success rate is high.		Even if the success rate is high overseas that also means there is still some possibility of failure, and that the number of failures is not zero. So I did not want to be the first in Japan.
New procedures are being carried out at other universities, but they cannot be used in your case.		If I am going to have an operation, this is my only option.

**Table 3. Life history**

<b>Year</b>	<b>Month</b>	<b>Event</b>
1954	2	Born. Grew up without any major illnesses.
1972	4	Graduated from high school and found a job.
1974		Married. Moved into a prefecture-run residence.
1975		Carried out administrative tasks for her husband who had started his own air conditioning related business.
1977		Birth of her first daughter
1979		Birth of her second daughter
1982		Birth of her son
1988		Moved into a house in order to have enough space to raise her children
1997	8	Tore a ligament in her knee while playing tennis.
1998	6	Hospitalized (June 21 <sup>st</sup> ) with symptoms of SJS
1998	10	Discharged from hospital. Almost completely blind.
1998	11	Examination at a university hospital revealed a perforation in her left cornea and she underwent emergency surgery. Discharged from hospital after about two weeks.
2000	1	Received a certificate identifying her as a person with a physical disability because of her visual impairment. [2]
2000	5	Began receiving a grade 1 disability pension [3].
2000	8	Entered a rehabilitation facility for people who have become blind.
2001	2	The head of the ophthalmology department met a British doctor named Liu at a conference in Japan and invited him to come to the university hospital. Her doctor referred her to Dr. Liu and she was diagnosed as a candidate for OOKP.
2001	3	Moved into her current "barrier free" house which had been newly built
2001	5	Graduated from the rehabilitation facility.
2001	8	Began to receive a pension from the system for the relief of victims of the harmful side-effects of medicines[4].
2001	12	Participated in a Japan SJS foundation event for the first time.
2003	3	Underwent the first OOKP procedure (discharged after about two weeks).
2003	6	Underwent the second OOKP operation and recovered 0.7 vision (discharged after about two weeks).
2003	8 ~ 11	Did various things like going to a baseball game, traveling, and visiting her hometown.
2004	6	Her disability pension was reduced to grade 3 as a result of her having regained her sight.
2004	10	Her pension dispensed by the system for the relief of victims of the harmful side-effects of medicines was terminated as a result of her having regained her sight.
2004	11	Filed an appeal for the reinstatement of her pension under the system for the relief of victims of the harmful side-effects of medicines.
2006	4	Her appeal for the reinstatement of her pension was rejected

The OOKP procedure allowed Ms Tachibana to obtain 0.7 vision. This cannot be said to be "normal" vision. But even among "healthy" people there are many whose vision is worse than 0.7. Compared to Ms Tachibana's vision before the operation, 0.7 can indeed be considered

close to “normal”.

The only positive result of the operation reported by Ms Tachibana and noted in table one is the happiness that comes from being able to see. This can be thought of as having two meanings. One is the happiness of having something that had been stripped away restored. The other is the pleasure brought by the sense of sight itself. In Sacks (1995) a case is described in which a patient who had been blind from birth acquires the ability to see in adulthood and experiences only pain and distress. Ms Tachibana's ability to describe becoming able to see as a benefit can thus be interpreted as having been influenced by her personal history and the fact that she lost her sight later in life.

Many negative results were described. Most of the issues that have been sorted into the categories of “visual function”, “daily maintenance”, “appearance” and “dentistry” can be addressed as problems of medical technique/technology. It remains unclear whether a procedure can be developed which will not lead to any of these negative effects. In the category of negative effects regarding visual function, Ms Tachibana reported that she cannot see when it is dim but when there is enough light for her to see it feels too bright and that she has to use two pairs of glasses, one for objects far away and another for objects close by. These problems are caused by the removal of the iris and crystalline lens. In the procedure developed by Strampelli in 1963 the iris and crystalline lens were not removed, but as a result inflammation occurred and the artificial corneas he implanted fell out. In 1987 Falcinelli altered the procedure by removing the iris and the crystalline lens, and the resulting OOKP approach has allowed the implanted cornea to remain in place for much longer. It therefore appears to be quite difficult to leave the iris and crystalline lens in place. Ms Tachibana's “field of view becoming narrow” is the result of the transplanted lens having been made cylindrical in order to allow it to be inserted into the tooth. In previous methods which did not use a tooth, however, the implanted artificial cornea tended to fall out. The fact that a tooth must be used to keep the artificial cornea from falling out it makes a solution to the problem of a narrow field of vision seem unlikely.

Negative effects classified under the headings of “appearance” and “communication with others” are secondary factors that result from technical issues, particularly the cosmetic characteristics of the procedure.

As a result of the issues discussed above, the emergence of artificial corneas which do not create these negative effects will presumably require the development of new technologies and cannot be attained simply by further improving and developing the OOKP procedure.

Another set of problems arising in a separate dimension from those discussed above are those classified as being related to the social insurance system and in particular the inadequacies of the relief system for the victims of harmful side-effects of medicines. The only criterion used under this system to measure the damage to the health of the eye is visual acuity, and only those whose visual acuity is less than 0.08 are eligible for assistance. As Ms Tachibana lost her sight because of SJS, a syndrome which is not well understood but occurs as the result of taking medication, she had been receiving a pension under this system. After the OOKP procedure, however, provision of this pension stopped because her vision had improved to 0.7. Her vision had indeed improved, but as is described in the table above it still

had several special qualities distinguishing it from “normal” sight. As a result this procedure failed to overcome the damage done to her health by the medication to such an extent that she states she had been more active before she regained her sight. She was nevertheless excluded from eligibility for assistance under the relief system for victims of harmful side effects of medicines based on the results of the procedure.

#### **4. The meaning of self presenting as a ‘cyborg’**

In this section I examine the background that led Ms Tachibana to call herself “Mekuraian”, which she associates with “cyborg”, and consider the connotations of this reference to “cyborg” contained in “Mekuraian” .

##### **4.1 Underlying circumstances**

In conducting interview surveys of members of the Japan SJS Foundation, Ms Tachibana is the only person I have so far encountered who self presents with a unique term of her own creation. This original form of self presentation was necessitated by the underlying circumstances particular to her case. As is evident from the fact that Ms Tachibana has discussed the origin of the term “Mekuraian” in connection with OOKP implantation, the background of this naming is related to this medical procedure.

To begin with, looking at the activities of the Japan SJS Foundation from its inception to the present time, this organization can be seen to have established three frameworks within which to position the problems faced by those suffering from this syndrome. The first is the framework of “illness”. This is applied not only to the acute early stages of the syndrome but also to its lasting aftereffects, and involves maintaining that the body of the individual in question is “ill” and not “disabled”, or in other words that they are still to be dealt with inside the framework of medicine. The second framework is “medication”. This is a meta-frame regarding the cause/mechanism required by the positioning of SJS as a disease. By connecting SJS to the harmful side-effects of medication its sufferers are made eligible for medical fees and pension funds provided under the relief system for victims of the harmful side-effects of medicines. The third framework is “intractable disease [“nanbyo” in Japanese]”[5]. “Intractable diseases” have been defined as part of a social system involved in the development of an understanding of their causes and new methods of treating them. The Japan SJS Foundation worked to have SJS recognized as an “intractable disease” and succeeded in getting the acute stage of SJS included in the scope of this system.

These frameworks are insufficient, however, to address the problems faced by Ms Tachibana. As stated above, Ms Tachibana obtained nearly “normal” vision by undergoing the OOKP procedure. Even though the nature of her vision after the operation was such that it was not sufficient to allow her to lead a “normal” life, the fact that she could see again was taken to mean that her “disease” had been “cured”. She is no longer eligible to receive funds provided under the relief system for the victims of harmful side-effects of medicines, and the pension that she had been receiving has been terminated. She can no longer receive this pension

because even if she suffers difficulties in her daily life these are no longer deemed to have been caused by “medication”. “Intractable disease” cannot be used as a frame of reference because this framework only applies to the acute phase of SJS through which Ms Tachibana has already passed.

In this way the three frameworks constructed by the Japan SJS Foundation do not provide a sufficient basis for Ms Tachibana to ground her actions and self presentation. Ms Tachibana's unique form of self presentation can thus be seen as stemming from her having undergone OOKP, a procedure that is rarely used by people in this organization.

#### 4.2 . Connotations

As was noted in part 1, the word “Mekuraian” was created by Ms Tachibana by connecting “mekura”, meaning “blind”, and a suffix, “ian”, which she associated with “cyborgs”. In order to consider the connotations of this word I will therefore break it down and analyze it in terms of these two component parts of “mekura” and the cyborg metaphor.

I will begin with “mekura”. This word had been used since ancient times to refer to people with impaired vision, but today it is seen as a discriminatory or derogatory term and is not used in official or public settings. It is impossible, however, to ban its use in the private domain of individuals. Even today the word “mekura”, with one of its characters obscured (e.g. “me××ra”), is used to express contempt, hatred or derision in online forums and publications such as underground manga that can be seen as points where the private domain crosses over into the public. When “mekura” is written in this way [“me××ra”] its meaning is perfectly clear to readers but an attempt is being made to avoid being criticized for the use of a derogatory term.

Ms Tachibana refers to herself with a term that is used in this way, calling herself “mekura”. This can be interpreted as an expression of her desire to be seen as a person with a visual impairment that results from the fact that while her vision is rated as “normal” using standard testing the quality of her vision is such that she has difficulty using her sight in everyday life. But among the various words for visual impairment she has chosen the derogatory term “mekura” rather than a neutral phrase. This inclusion of “mekura” in the self presentation “Mekuraian” must be thought of as an intentional reference to the generally negative connotations of that word, in other words an intentional choice of a term with connotations of contempt, hatred, and derision.

However, the “mekura” in “Mekuraian” cannot be seen as expressing only a negative view of her self-presentation. This is because it is spelled out clearly as “mekura” and not written as “me××ra” or another phrase designed to cover up the blindness. This is similar to the way people who have been called “deaf” or “queer” have turned this around by using the same words to present themselves but capitalizing them, i.e. “Deaf” and “Queer”. Ms Tachibana's use of the word “mekura” is both an indictment of society for having placed her in circumstances that are viewed negatively and a positive expression of her will to overcome these difficulties. In this sense Ms Tachibana uses “mekura” with a capital “M”.

From the above the “mekura” in “Mekuraian” can be seen as a term with which Ms

Tachibana positions herself as a person with a visual disability even though she now possesses almost “normal” vision, and expresses ambivalence towards this state of affairs by evoking contempt, hatred and derision and at the same time asserting her desire to bring this state of affairs to the fore and overcome it. So what is it that Ms Tachibana is trying to express by describing herself to others with this word that disparages her own body? I interpret in this an expression of anger that I will discuss further later in this paper.

Next there is the reference to “cyborg” made with the suffix “ian”. I think Ms Tachibana's reference to cyborgs has the following four connotations.

**A. A body that has become deviated by losing its “naturalness”**

As is noted in the citation from Morioka (2001:12) in part 1, on seeing a person who is ill and surviving through the use of machines some people feel that this individual has lost her humanness and is comparable to a “cyborg”. There is a sense that when the shape of a human body is altered the result of this interference is not something natural but a body which has lost the essential nature that defines human beings. In Ms Tachibana's case, having a tooth in her eye is something unthinkable in a natural body. If it did somehow arise in nature it would be considered a deformity. And while this tooth contains no electronics, it is embedded with PMMA, a material that does not naturally exist in the human body. Ms Tachibana's external appearance is therefore also different from what could be seen as “natural”.

**B. Human intervention**

Both deformities present at birth and illnesses contracted later in life arise in places beyond human control. In contrast, deviated bodies *are deviations* that are created by surgical procedures, in this case the manipulation of a body based on the intention of human beings to restore lost sight. This deviated body was created when human beings used technology on a human body with a particular purpose in mind.

**C. A deviated body as a success**

There are cases in which a body is deviated and the body that results from the technological intervention is deemed to be a success. This deviated body does not arise through a failure such as that of Dr. Frankenstein. Nor are its deviations the result of unintended side-effects or an iatrogenic disease. To the doctors involved in Ms Tachibana's treatment, the procedures had all passed an Institutional Review Board (IRB) inspection and the results obtained were in line with the expected outcome of the OOKP procedure based on trials and previous cases. For Ms Tachibana too the results were as she had been told they would be before consenting to the procedure and were described as a successful outcome after the operations had been performed.

#### **D. Imperfect Imitation**

There are cases in which sight obtained through technology cannot be anything but imperfect. Considered from the point of view of Rene Girard (1961), when a patient goes through an OOKP operation to obtain his or her sight, the patient aims for the kind of sight and lifestyle which “my body as it was before SJS” aimed to have. If this imitation/desire were perfectly realized, since the resulting body would presumably be just like a natural body and would not have lost any of its humanness, no deviation of the body would have taken place. In cases like the use of eyeglasses, contact lenses, or artificial crystalline lenses, if no inconvenience is encountered in daily life regarding the technology or the vision obtained the body of the individual in question will presumably not appear to him or her as deviated and there will be little room for doubt about the success of the techniques/technologies employed. The vision obtained as a result of OOKP has been determined to be a successful form of human intervention, but while this vision is close to “normal” the quality of the sight experienced by those who have undergone this procedure cannot be said to be sufficient in their daily lives.

With this in mind I think we must view Ms Tachibana's use of “Mekuraian” as expressing anger at the fact that while her procedure may have been deemed a success the result is nonetheless imperfect, and that since this procedure was an intervention which followed a formal medical process even if she wanted to complain the basis on which to do so has been taken away along with the words with which to express her dissatisfaction. I think this anger can be seen in her use of the derogatory “mekura” rather than a more neutral term to refer to herself as a person with a visual impairment. In other words, she has been made a person with a visual impairment as a result of an intervention that was deemed medically successful. It may therefore be better to view Ms Tachibana's emphasizing her own status as “mekura” as containing an element of aggression and in this way differing from the use of “Deaf” to refer a particular ethnic group and culture.

#### **5. Summary**

We have seen that for Ms Tachibana, a patient who had nearly completely lost her sight as a result of SJS and later recovered nearly “normal” vision by undergoing an OOKP transplant operation, the three frameworks of “illness”, “medicine” and “intractable disease” established by the Japan SJS Foundation do not provide a sufficient basic framework for action and self presentation. Here Ms Tachibana has created her own term of self presentation, “Mekuraian”. The “mekura” in “Mekuraian” is an indication of Ms Tachibana's desire to position herself as a person with a visual impairment, a desire which has arisen because of the fact that while her vision is considered “normal” the quality of sight she experiences is imperfect. This use of “mekura” evinces an ambivalent attitude towards this state of affairs, expressing both contempt, hatred and derision and a desire to focus on this impairment and overcome it. The “ian” in “Mekuraian” is a reference to “cyborg”, and can be thought of as being connected to the feeling that her body has been deviated and lost its “naturalness” following her operation and to her anger regarding the fact that even though the result of her operation was not a

perfect restoration of her body it was nevertheless deemed a medical success and as a result grounds for her to register her dissatisfaction about the resultant state of affairs have been taken away from her. This anger is connected to her use of the derogatory term “mekura” and invests the self presentation “Mekuraian” with an element of aggression.

In future I would like to consider more deeply the possibility that apparatuses created to protect patients/experimental subjects such as informed consent, one of the central concepts in bioethics, and the IRB, may in some cases function as apparatuses which take away the means by which patients/experimental subjects are able to express themselves.

## Notes

[1] SJS occurs at an estimated rate of 1-10 people/1,000,000 and can effect individuals of all ages. Its cause/mechanism are not yet understood but it is thought to be an infectious or allergic reaction of the skin. In most cases it appears to be caused by medication, but it is difficult to predict this reaction before medication is prescribed. The symptoms of SJS are a high fever, erythema exudativum multiforme breaking out over the entire body, and ulceration at transitional regions between the skin and membranes such as the lips, mouth, eyes, nose and external genitalia. After skin symptoms have subsided, lasting effects can remain in places such as the eyes and respiratory system, and death can result from damage to multiple internal organs. The overall mortality rate is 6.3% and 20-30% in cases where symptoms are severe and include toxic epidermal necrolysis ( Pharmaceutical and Medical Safety Bureau, Ministry of Health, Labour and Welfare 2005; Japanese Intractable Diseases Information Center Website).

[2] “Anomalies of visual perception” regulated under the Act on Welfare of Physically Disabled Persons are those in which impairment is permanent and at least one of the following criteria are met: a. vision is below 0.1 in both eyes, b. vision is below 0.02 in one eye and 0.6 in the other, c. the field of vision in each eye is narrower than ten degrees, d. more than half of the field of vision seen with both eyes has been lost.

[3] Disability pension is a pension paid to people within the public pension system in order to deal with obstacles to daily life in cases in which an individual has acquired a disability through injury or illness and this disability is severe enough to meet stipulated requirements. The disabled employee pension is a public pension paid to members of an employee pension plan and is graded on a scale of 1 to 3 determined by the severity of the disability.

[4] This system is administered by the Pharmaceuticals and Medical Devices Agency, Japan. This agency oversees a variety of activities including the provision of relief to victims of harmful side effects of medicines, the conducting of studies related to the promotion of the development of new pharmaceuticals and the approval of new drugs, and the provision of relief for the victims of contaminated products derived from biological materials. By dispensing funds for such things as medical fees, disability pensions, and survivor's pensions, the system of relief for victims of the harmful side-effects of medicines provides swift assistance, separate from any civil liability, when an

individual's health is harmed by medication even though it was dispensed correctly. Injury to the health of the eye is covered if the resulting vision is less than 0.08.

[5] The Ministry of Health, Labour and Welfare set up “Nanbyo taisaku youkou” (Outline of policies dealing with intractable diseases) in 1972 and has conducted the following activities:

1) Promotion of studies/research. 2) Creation/maintenance/modification of medical and other facilities. 3) Reduction of the burden of medical fees paid by individuals. 4) Cooperation/ improvement regarding the insurance/medical treatment/welfare provided at the local level. 5) The promotion of welfare policies to improve quality of life. In this outline an “intractable disease” is described as “a disease the cause of which is not understood, has no known treatment, and is expected to have lasting aftereffects” and “a disease whose chronic symptoms cause not only economic but also heavy emotional/psychological burdens on the family of the person afflicted as a result of the large amount of care required”.

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