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Managing Stigma by Visual Presentation of Self

Stigma is a Greek word that in its origins referred to a kind of tattoo mark that was cut or burned into the skin of criminals, slaves, or traitors in order to visibly identify them as blemished or morally polluted persons. These individuals were to be avoided or shunned, particularly in public places (Healthline Network Inc., 2007).

Later, in Christian times, two layers of metaphor were added to the term: the first referred to bodily signs of holy grace that took the form of eruptive blossoms on the skin; the second, a medical allusion to this religious allusion, referred to bodily signs of physical disorder (Goffman 1963, 11). Stigma was a mark of the sins of its carrier or his forefather's.

Modern usage of the words "stigma" and "stigmatization" refers to an invisible sign of disapproval which permits "insiders" to draw a line around the "outsiders" in order to demarcate the limits of inclusion in any group. The demarcation permits "insiders to know who is "in" and who is "out" and allows the group to maintain its solidarity by demonstrating what happen to those who deviate from accepted norms of conduct (Falk, 2001). Stigmatization is an issue of disempowerment and social injustice.

Erving Goffman considered individuals whose stigmatizing attributes are not immediately evident. In that case, the individual can encounter two distinct social atmospheres. In the first, he is *discreditable*--his stigma has yet to be revealed, but may be revealed either intentionally by him (in which case he will have some control over how) or by some factor he cannot control. Of course, it also might be successfully concealed; Goffman called this *passing*. In this situation, the analysis of stigma is concerned only with the behaviors adopted by the stigmatized individual to manage his identity: the concealing and revealing of information. In the second, he is *discredited*--his stigma has been revealed and thus it affects not only his behavior but the behavior of others. Goffman points out that when term stigma is used to refer to an attribute that is deeply discrediting, it should be seen that a language of relationships, not attributes, is really needed. An attribute that stigmatizes one type of possessor can confirm the usualness of another, and therefore is neither creditable nor discreditable as a thing in itself (1963, 13).

Epilepsy, a common neurological disorder characterized by recurring seizures, is associated with various social stigmas. In my presentation I concentrate on twin

brothers, who have a rare and difficult form of epilepsy, progressive myoclonus epilepsy (PME1). The twins got their first epileptic seizures in the age of fourteen and their final diagnosis on Unverricht-Lundborg disease was made when they were seventeen.

Goffman mentions three different types of stigma: abominations of the body, blemishes of individual character and the tribal stigma. He says that all these various instances of stigma carry the same sociological feature: an individual who might have been received easily in ordinary social intercourse possesses a trait that can obtrude itself upon attention and turn those of us whom he meets away from him. He possesses a stigma, an undesired differentness from what we had anticipated (1963, 14 - 15).

In the case of epilepsy it is often so that you cannot see the stigma from outside. The person might not have seizures in public places. He or she is looking like anybody and everybody else. Many people who have epilepsy keep it as a secret. Only their closest family members know about it and even they might avoid talking about it. The stigma is actually created by making it a secret.

Goffman (1963) asks, how does the stigmatized person respond to his situation? He gives examples, where people are trying to correct what they see as the objective basis of their failing through medical treatment like plastic surgery or psychotherapy etc. (p.19). The stigmatized individual can also attempt to correct his condition indirectly by devoting much private effort to the mastery of areas of activity ordinarily felt to be closed on incidental and physical grounds to one with his shortcoming. He might use his stigma as an excuse for ill success that has come his way for other reasons. Also he might see the trials as a blessing in disguise, especially because of what it is felt that suffering can teach about life and people.

In the case of the brothers in this presentation it is a question of interaction between them and their so called normal friends and more precisely interaction through visual communication. They have been going to the art school of children and young people since they were seven – eight years old and one stopped going there in the age of fourteen and the other one a year later. The one who stopped first said that the art school sucks.

The first epileptic seizures came, when the brothers were fourteen. Jukka (the names are changed) had his first fit in May and Risto in July. Both were told in the hospital ward by the doctor that they are not going to be able to drive a lorry or steer an airplane, because the European Union directives forbid certain professions, if you have been diagnosed to have epilepsy. They had never dreamed about being a lorry driver or a pilot, so that piece of information did not worry them too much, but what made

them worried was the fact that since that very moment they belonged to a different group of people than their friends and family members.

Goffman (1963) writes about wise persons, from whom the stigmatized person can expect some support. He describes the wise persons to be the marginal men before whom the individual with a fault need feel no shame nor exert self-control, knowing that in spite of his failing he will be seen as an ordinary other. Goffman gives an example, how a call girl might be accepted by artists, writers, actors and would-be intellectuals as an off-beat personality, without being a curiosity (p.41).

The “wise persons” in the life of Jukka and Risto happen to be their longstanding friends, who also are a little bit in the margins of the mainstream. Their social life continues as before, even if there are some and increasing limitations in their everyday life. The other boys start trying out drinking in the age of fifteen, but the twins cannot drink alcohol because of their rather strong medication. They decide to take their first tattoo and go to a professional tattooist.

Visual actions as communication



rhö, tries out dressing up like a girl. He goes around the l photographing him. The photos are sent to a small circle art making images of Hörhö and themselves and sending

The brothers are back to their previous way of thinking by visual language and drawing both on computer and on paper. It is an interesting question, whether their friend Hörhö would have dared to show himself as a girl in some other company. The twins with a strong stigma were safe company to share a lust of dressing and making oneself up into an opposite sex. The action was made vaguely in a context of “art” or performance and it felt more acceptable than doing it “seriously”. According to Goffman the normal person who is becoming wise may first have to pass through a heart-changing personal experience (1963, 41). I suggest that the strong action by Hörhö can be seen not only as trying out, how it feels to dress like a girl, but as a

gesture to offer oneself as a defiant in public space and thus making himself available to the stigmatized one.



a girl Jukka created an image, where Risto is sitting by his and outside the house is a mailbox on which it is written was circulating among small group of friends.

Hörhö is interested in hip-hop culture and some other boys in the group are also doing their own rap. There are some young African originated men, who are seriously rapping in the town and are quite good at what they are doing. So the twins create an image, where Hörhö is not succeeding in his rap whereas the other black rap artist is looking proud and strong.

Goffman says that it is actually the “normal” one, who decides whether to go along as “the wise man”. Goffman puts the wise persons in two categories: those whose wiseness comes from working in an establishment which caters either to the wants of those with particular stigma or to actions that society takes in regard to these persons. A second type of wise person is the individual who is related through social structure to stigmatized individual – a relationship that leads the wider society to treat both individuals in some respect as one (1963, p.43). By making images of Hörhö and also



ite their friend to become an equal to them and when by accepting the image making, he takes the final step of the stigmatized twins to whom he is related through

There is visual joking about being in music business, about big appetite and about passion to play computer games. Although the circle of friends, who have access to images is somewhat larger than only these three boys, the images are only about them three. Around the same time the twins made a video called “Gaming” that is about passionate playing of video and computer games. They filmed each other, their little brother and couple of friends and their teacher on the video course. The film was made

in the art school and shows, how they use autobiographical material also in their work in the college.

As we remember the doctor had told the brothers that their future will not be in public transport. It became soon clear that many other professions were impossible to think about as future career. According to Goffman (1963, 47 – 48) individual who become stigmatized late in the life presumably will have a special problem in re-identifying himself. Concept “late in life” is rather relative and can mean also youth; you have been born as “normal” and something changes your whole life in the age of adolescent. The twins had been planning to study building branch and chemistry, but it became clear that it would be impossible because of the epilepsy. Their career advisor suggested them to think about art studies as their teachers had reported that they spent more time in drawing, when they should concentrate on other subjects. So they decided to apply to art school not so much because of the desire to study art, but because there seemed to be very few interesting alternatives available.

They were accepted in college and started art studies autumn 2007. Only couple of months later one of them realized that he had continuous problems with his balance and he was falling down several times suddenly while walking. He contacted neurologist and soon after the diagnosis of Unverricht-Lundborgs disease was made. The twins were told that it is a question of a progressive disease without any known cure. One of the most obvious symptoms of the disease is decreasing ability in muscular control, especially hands can be very shaky. The disease is leading gradually into wheelchair.

Goffman points out that in the case of somebody realizing suddenly that his life turns out to be different than he has supposed, the medical profession is likely to stigmatize the infirm who he is going to have to be (p. 49). In their work they would tell them, who they are likely going to be, but they would not say what they can become. Nobody said that they could not become



In January 2008 the brothers took a course called Art of Encounter. The purpose was to take artistic actions in places, where people are normally not meeting art. They organized an encounter with art for the litter man. They sprayed a golden snowman partly inside, partly outside a big container and said that it would be a surprise for the man emptying the containers. The work is a strong statement about being partly in the litter container, only parts of the legs still hanging outside. They were presenting the work for the rest of the course participants, but did not explain it more than that it was

a surprise for the litter man. Their course mates thought that the work was rather amusing.

April 2008 the brothers made a performance “Studying Art”. They came to the stage that was white and had only two chairs on it. They seated themselves on the chairs, one starting to roll a cigarette and the other one to draw the one rolling a cigarette. They did not say anything and the performance took as much time as it takes to roll a cigarette. Then they walked away.

They did not do much in the school after the performance and even though they started the term following autumn, they resigned from the art school after one month school start. Meanwhile they had gone through thorough medical research including brain stimulations and psycho neurological tests etc.

Goffman writes about public presentations given by different particular stigmatized groups. There are publications which give voice to shared feelings, consolidating and stabilizing for the reader his sense of the realness of “his” group and his attachment to it. The publication also serves as a forum for presenting some division of opinion as how the situation of the stigmatized person should best to be handled (p. 37). Most of the stigmatized persons join association that is especially founded for people with similar stigma category. The brothers refused to be associated with any medically stigmatized groups and did not want to go to rehabilitation that was arranged for people with epilepsy, neither read any special material in publication form. They used the internet for collecting information about the disease.

When the brothers resigned from the art school, they left a society which was tolerant and where they were not looked upon as stigmatized persons. Many of their works were received as interesting insights to different phenomena in society and life in general. At the same time in the art school there was also a female student, who had narcolepsy and epilepsy. So one could make a question, why to leave a safe society, when there is nothing else that could replace it?

The Question of visibility

There are unlimited ways to work in the field of contemporary art. One concept of art is that anything one takes into art world becomes art. The brothers in this case study decided to leave the official art world, but did not leave the world of art.

After a period of time outside the art school, they decided to buy a set of tattooing needles and ink. One of them made a spider web into his knee and the other one some stripes on his arm and initials on the other arm. He also made a complicated image of a snake wearing a hat and curling around a cactus. The tattooing process was rather

difficult mainly for two reasons: it needs a great deal of skill for anyone to make a tattoo and on the other hand the twins have occasional problem in controlling their muscles, so their hands were not stable. They also invited their friends to make own tattoos and did not hide the difficulty of controlling the electronic needle. For couple of weeks they had a tattoo studio at their home and a group of young people were trying out to make tattoos and finding it incredible difficult.

Afterwards the brothers were talking about tattoo as a form of art. They had collected a lot of information about tattoo traditions and were aware that in Japan the whole body tattoos were created first by former prisoners, who wanted to cover their stigma marks by overdoing them with much larger images. They argued strongly that tattoo is art also, when a tattoo artist is using similar images on different individuals: it is the individual, whose skin and way of being make all tattoos different even if the image would be the same.

When the brothers were talking about tattoo as an art form, it somehow reminded the creek term *tekhne*. They spoke about skillfulness, ability to master the needlework, the difficulty in drawing into skin which is a very uneven surface. You need a special way of knowing while making and you cannot learn it just by reading theory, even if you need to know the tradition also from theoretical, or better to say from a narrative point of view. They did not think that tattoo is somehow different or less valuable form of art in comparison to other art forms.

I come from a contemporary (read traditional) art world and realize the limitations of my background. For me it is difficult to accept the world of tattoo as such as equal form of contemporary field of art. I can see that the action of making tattoos by the twins could be seen as an art project if it was taken in a form of documentation into art world. But to see it as making art in itself creates attitude problems in my concept of art. The position is alike what Goffman describes when he talks about social deviants. According to Goffman social deviants often feel that they are not merely equal to but better than normals, and that life they lead is better than that lived by persons they would otherwise be (1963, p.172). At that period of life the twins do not see the established art world very interesting for them and on the contrary they feel closer to the art world of tattoos. One could make various interpretations about why they left the art school. It could be seen as an escape from increasing difficulties in fine motorial skills. It could be interpreted as consequence of serious depression because of progressing disease. Their own explanation, which might be true or then a cover for an untold or subconscious reason, is that they were not interested in art in the way it was introduced at the college.

Yvonna S. Lincoln (1997) is writing about the new generation, who is more attuned to visual images than to written word. She is speaking in the context of changing paradigms, but I can see how the same phenomena will change the concept of art. We have the young generation, who have been taking art classes and at the same time grown up with digital technology. They have become visually literate as all the well planned curriculum expects them to do. So they use visual language as one way of communication and they form their concept of art according to their own experiences and interests. They are in a way deviant in the formal art world, but they do not care about it. They have no wish to enter the official field of contemporary art.

Visually literate people have one more way to manage a stigma. In the case of twin brothers the boys are not making direct images about their stigma. They are mocking themselves and their friend about music making, computer playing, eating. They make a clear statement about studying art in their performance which is an interesting act in a sense that it speaks the language of established art world and at the same time it ridicules the art world. The performance shows that the brothers know the language that they should use and the environment where they should move about, but they just do not have a real interest in staying in.

Goffman argues that it is not to the different that one should look for understanding our differentness, but to the ordinary. The concern should be according to Goffman for ordinary deviations from common (1963, 152). What the brothers are representing in their computer images are the ordinary problems of young people: overweight, dependency on gaming, failing in music performance (rap), wondering about one's sexual identity. What makes difference in this case is the openness with which the boys are dealing with their common problems.

The actual dealing with one's stigma enters the picture in the making of tattoos. The boys are fully aware of their disease and the difference it makes in comparison to their friends. They are also aware of the traditional way of making someone's stigma visible. Tattoos are very interesting phenomena, because at the same time they carry the tradition of labeling a deviant person and on the other hand it is very trendy to have tattoos. Even nice grannies may have tattoos and successful businessmen and – women can have tattoos, teachers and doctors may have them. So in a way by taking a tattoo you do not do anything especially rebellious or extraordinary nowadays.

But by making your own tattoo with an unstable hand, you visualize something that a part of your social environment know about, but perhaps not want to be reminded too often. It is also a way to feel physical pain during the process of drawing the ink into one's skin. The pain of a stigma is felt psychologically by all of those, who carry one. Still it does not necessary have to be a dominant state of mind for the person who

possess a stigma. Goffman reminds us that stigma involves not so much a set of concrete individuals who can be separated into two piles, but rather we should look at the question as a pervasive two-role social process in which every individual participates in both roles, at least in some connections and in some phases of life. The normal and the stigmatized are not persons but rather perspectives (1963, 163 – 164).

And when it comes to see different perspectives, one has to realize that stigmatized persons differ from each other in many more ways than they are similar. After all the twins in this study have much more in common with their friends than with other unknown individuals, who suffer from the same disease with them. Their friends speak the same visual language, they share practical jokes and some kind of collective denial of the middle-class ideal. With the friends the brothers play both the role of deviants and the “normals” and sometimes it is very hard to tell, which is which one.

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