

Illness Beyond Description:

Three narratives and the *ars vivendi* of patients with CRPS (Complex Regional Pain Syndrome)

Mayuko ONO*

**Graduate School of Core Ethics and Frontier Sciences*

Ritsumeikan University, Kyoto, Japan

**Research Fellow of the Japan Society for the Promotion of Science*

I. Introduction

The aim of my research is to reveal the present and future issues of patients with Complex Regional Pain Syndrome (CRPS) and to provide a support system for them using their narratives.

I would like to talk about CRPS, an illness of which patients with CRPS themselves say is “impossible to make sense of.” More specifically, I will discuss what it means for CRPS patients to talk about their experiences and about their art of living, their *ars vivendi*.

II. What is CRPS?

1. About CRPS

First, I wish to simply describe CRPS, because many people do not know about this illness. CRPS is an intractable illness that is characterized by chronic, severe pain. It is caused by nerve injuries as a result of medical accidents during procedures such as operations or blood collecting or as a result of bone fractures or sprains caused for example by traffic accidents. As a result of such injuries, sensory nerves and motor nerves are morbidly changed.

Epidemiological surveys of CRPS have never been conducted in Japan because the illness itself has only been newly identified and its diagnostic criteria have not yet been established. Therefore, we do not have a concrete number of how many people have actually contracted the disease in Japan. According to Dr. Sumitani’s report in CRPS seminar in 2008, the incidence rate of the illness is five out of one hundred thousand (0.005%). However, it is important to note that this number seems to be based on the medical records of only a few special hospitals for chronic pain.

There are few doctors who can diagnose the symptoms of CRPS because of the lack of recognition of the disease. Special organizations that diagnose CRPS only exist in big cities.

Undoubtedly, there are “latent suffering patients with CRPS” who have never been diagnosed. According to a survey by RSDSD, a support group in the USA for patients with CRPS, every year one hundred thousand people suffer from CRPS as a result of medical operations. In South Korea, there are fifteen thousand to twenty thousand patients who have CRPS. Considering the rate of Korea, forty thousand people with CRPS probably exist in Japan. The illness covers all age brackets, from the young to the elderly, and both sexes. However, it seems that the rate of CRPS for women is higher than that for men, except in the category of patients injured in war.

Patients who have stable symptoms have to see the doctor every two to four weeks. However, gravely ill patients must go to hospital three times or four times a week. Furthermore, in some severe cases, the patients’ pain metastasizes to their whole body and they have to stay in bed and be cared for, because they can no longer use their arms and legs. A medical remedy of this symptom has not yet been established. For medical care, patients may receive surgical treatments, like a nerve block to the spinal cord or neuro-destruction by surgery, in order to control pain. They may also get pharmacotherapy with drugs like morphine, lidocaine, pregabalin and so forth. People who live in countryside, in particular, have in consequence of this disease a lot of physical and economical burdens.

2 . What pain as a main symptom exactly means

I would like to explain a little more about what it means to have pain as the main symptom. It is said that pain is the greatest of all the suffering. Darwin pointed out that pain is related to a common and universal biological circuit. As Schweitzer said “pain is even a more terrible lord of mankind than death itself.” In Japan, there were two lawsuits that were related to pain in the four judgments on the Tokai University euthanasia case in which active euthanasia was approved. In consideration of these points, we can understand that pain is a primitive stimulus and imagine how it leads to suffering equal even to that of death.

Pain has three functions: warning, avoidance, and defense; all three have important roles for our existence. Therefore, it is said that it is difficult for us to acclimate to pain. CRPS is characterized by severe, burning, deep and lasting pain. Pain is sometimes needed for living, but it brings much and prolonged suffering for patients with CRPS because the pain of CRPS is separate from the three basic life functions mentioned previously. American and Korean mass media have reported that the “pain of CRPS is stronger than that of terminal cancer,” that “CRPS patients have crossed a river that they never cross back,” and that “the pain is a death throes that does not die.”

Now, I would like to talk about the significance for patients with CPRS in telling of their experience of living with the illness. I would also like to discuss the patients’ *ars vivendi* as

demonstrated by their narratives.

The period of investigation is from July to November 2007. I conducted semi-structured interviews with seven patients with CRPS to reveal what patients with CRPS are suffering and how they reconcile with those sufferings (Table1).

During the interviews, I listened to the interviewees talk about their bodily symptoms at first, then about the course of their treatments, the difficulties that they have in their daily lives, the responses from people around them, and how they feel about these experiences. I let them speak about these issues as they liked.

III. Three kinds of narratives of patients with CRPS

I have classified the narratives of patients with CRPS into three types.

The first type is a narrative that leads to positive effects for society and patients themselves. This type I have named “narrative as sense making.”

The second type is the narrative of *shikataganai*. I cannot find suitable word in English for *shikataganai*. It is not “resignation” in its negative meaning, nor is it “acceptance.” Neither does it have the positive meaning of avoidance for those telling their narratives. Moreover, it does not impose the values good/bad or positive/negative on the narratives. *Shikataganai* is a unique philosophy of the Japanese people: things are accepted as they actually are. As you may be familiar with the Japanese word “*mottainai*”, which refers to the remorse felt when something is wasted. Although the word has been popularized worldwide by the Kenyan environmentalist and Nobel Prize winner, Wangari Maathai, the meaning of *mottainai* arose from practices peculiar to Japanese culture, so it is hard to adequately translate the word to any other language. For this reason, “*mottainai*” is transcribed in roman letters. Following the example of “*mottainai*”, I would like to call the second narrative type “narrative as *shikataganai*.”

The third type is a narrative that is forced by external power. I would like to call this “narrative as being held back.” Well, let me tell you about each narrative in detail.

1 . Narrative as sense making

I asked interviewees the reason why they kindly cooperated as informants in my study. Some gave compassionate answers like “I want my experience to be useful for the improvement of social recognition about CRPS,” or “I don’t want anyone to suffer from the illness like me.” Also, from patient’s family members and a representative of patient groups, I got comments like “I have seen her smile more after she was interviewed,” and “it was a good experience for them to be an interviewee.”

In *The Wounded Storyteller*, Professor Frank says, “people give their experience of illness to try to lead the others to follow them through their narratives.” Here, I can approve that meaning of narrative, it gives them social meaning and leads to positive changes for the

storyteller.

2. Narrative as *shikataganai*

The next type of narrative is “narrative as *shikataganai*.” In the other words, it is “the thing that is never changed by narrative.”

(1) Pain as metaphor and real pain

There are many kinds of chronic pain. For example, concerning pains of somatoform disorders, which means, symptoms of proxy, previous studies have focused on finding the meanings of the illness in medical sociology or clinical psychology. These kinds of pain are only metaphors that represent different forms of psycho-social suffering depending on their position. On the contrary, the pain of CRPS is physical pain that is more real than metaphorical.

I would like to explain the pain of CRPS more by using some figures. This is a general chronic pain. Chronic pain is composed of physical, social and psychological suffering, all of which overlap each other (Figure.1). On the other hand, CRPS pain can be represented by this figure. The first one is physical pain, in short, infringement stimulus and a sense of pain as a result. The second one is social suffering because of pain. The third one is psychological suffering from physical pain and social suffering. These three components are united all together and organize the pain of CRPS patients. See (Figure.2).

In the case of general chronic pain, it may be possible to remove or reduce pain if someone gives physical or psychological or social support to the patient. However, in the case of CRPS, physical pain still remains even if someone gives the patient psychological or social support. And one can see from the patients' narratives that physical pain is experienced as the greatest part of their whole pain.

Some previous studies in the fields of medicine nursing have reported that a patient's chronic pain can be reduced by a doctor's consultations or by peer counseling. However, I think the chronic pain referred to in these studies is general chronic pain.

Here, I do not want to delve into what the cause of pain is. But, I would like to show and confirm that there are two kinds of narratives related to pain: 1) there is pain that is dissolved by narrative, and 2) there is pain that is not dissolved by narrative.

(2) The things change by narrative / Not changed by narrative

From now on, I would like to use the Numerical Rating Scale (NRS) to show how patients change with their illness.

First let us look at the change of pain and the feeling of patients. In the interviews, I asked patients to evaluate their sense of life satisfaction by using an 11 point Numerical Rating Scale (NRS) ranging from 0-10. Evaluations of pain showed no change before and after the

interviews, but evaluations of feelings show a positive change after the interviews.

This result reveals that the physical pain of CRPS is a problem that should be considered biologically. On the other hand, it suggests that even if there is no hope for a medical recovery of the patients' bodies, there is a possibility for patients to ameliorate their social suffering from the pain and their psychological suffering from physical pain and social suffering in order to reduce their suffering in a larger sense. At the same time, this result shows that some parts of their pain is changed by their experience of talking about their illness, but also that a part of their pain remains unchanged by the narrative.

Another interview topic was the transition of CRPS patients' satisfaction in their lives. I asked patients to evaluate their sense of life satisfaction using NRS. The average scores of the patients were 6.8 before the onset of CRPS, 1.2 after the onset of CRPS, and 5.6 at the time of the interview. The result has a V shape.

This result reveals that the severeness of Activities of Daily Living (ADL) does not always correlate with Quality of Life (QOL). I asked patients why and how their life satisfaction changed as it did; from their narratives, I extracted four concepts: encounters with peers; awareness of what they have acquired; conversion of value; establishing of targets. These elements had some positive effect on their life satisfaction.

For example, some patients talked about their lives and themselves affirmatively: "I think I can accept my life satisfaction at 10 points"; "I like myself because I have become a better person than before, when I couldn't be grateful for others' kindness".

However, negative words were heard for chronic pain: "it's like a hell"; "I hate this illness"; "I can never accept it." Some interviewees were still pursuing the meaning of their illness, others gave up trying to find meaning to their illness and accepted it just as it is. Even though they have an awareness of what they have acquired, this is not equal to finding the meaning of their illness. Thus, I think there is illness of which sense cannot be made of with any word.

I would like to ask: what is the significance of talking about one's illness, except for adding social meaning to its context, as is the case with patients with CRPS? I think that we cannot expect that patients will be able to change the meaning of their illness through narrative, because CRPS is an illness that is beyond description.

3.Narrative as being held back

I would now like to talk about the third type of narrative, which I call the "narrative as being held back." This third narrative could be a solution for those who still cannot find the meaning of their illness.

(1) The *ars vivendi* of patients with CRPS

I want to introduce an episode about one patient with CRPS to explain narratives of the type “narrative as being held back”. The patient is in her sixties and has symptoms of CRPS caused by an operation. I will call her “Mrs. A.” In her interview, she says of her own pain that it is as if she was “struck with metal ropes and bitten by dogs,” and “feels like dying.” Many times she asked her doctor to amputate her arm which causes the pain.

First, she wanted others to be able to understand her pain. Her children also cared about her and asked her several times, “Mom, are you ok? Do you have pain now?,” to try to understand her pain.

However, one day, in the period when she was getting general medical treatment, and recognized that she could never overcome her illness, she felt pressured by her children’s questions about her pain. She has terrible pain twenty four hours a day. She always has pain. If she says honestly that she has pain, her children must feel sad. But she cannot afford to tell a lie and say “I’m OK.” These days, her children have stopped asking and never ask her about her condition any more. She said “what makes me sad is being asked about my pain condition.” “But my children never ask me now; I’m so thankful for their consideration.” She smiled. In the course of the interview, it was revealed that her husband had actually said to her children “do not to ask about her condition because she always has pain.” She was so happy to know that.

The usual ideal of care is said to be to ask suffering people, “how are you now?” without ignoring them. However, patients with CRPS sometimes get embarrassed if they are asked about the present moment, because their pain is always on-going. Chronic pain is infringing and momentary, but also eternal and makes people lose the sense of temporality. Mrs. A’ family converted the ideal of care from “caring = asking” to “caring = not asking.” That is their *ars vivendi*.

(2) Internalized illness / Externalized illness

Let’s look at the general view in previous studies about illness. The first comprehension is “patient A.” In this case, the person and disease are not differentiated. Then, a new theory was born that recognizes illness as a self–affinity, like “A with illness.” It is as if illness is one part of that person and internalized like “A is living with _____,” so then the focus is on finding the meaning of the personal experience of illness and of the illness itself. However, the eight patients with CRPS I interviewed separate their pain from their selves. In other words, they externalized their illness and talk about pain as outside of themselves.

I would like to show an example to help you imagine externalization. For example, depression or phobia is characterized by a state in which patients cannot separate their symptoms from their selves. Patients are suffering because they cannot differentiate their

symptom from themselves or their inside.

The narrative of patients with CRPS is a story of their acceptance of themselves, but not a story of their acceptance of their pain. It suggests that living with severe chronic pain is an experience in which patients have to put the pain outside of themselves. They cannot flee from their pain for even one second, so they put the pain outside of themselves, and not take it in. This is one example of the *ars vivendi* of patients with CRPS.

This is related to the case of Mrs. A: when patients have to reply about their pain to someone's asking, they need to accept their pain which was once divided and externalized. It becomes obvious not only in a domestic setting, but also other aspects of daily life and social life, even more so. Patients have to prove positively that they have difficulty with pain to get some support from social welfare or employment systems, as CRPS is an illness that has invisible symptoms, lacks social recognition, and is difficult to explain. To get care from others or to advocate about the illness, the patients must take on pain that they usually keep away from themselves unconsciously. Furthermore, the patients must consciously accept their own pain. It is not excessive to say that talking about the illness itself produces pain for them.

The externalization of pain by patients' with CRPS is equivalent to avoid the sense of time from their pain. In other words, externalizing pain is crystallization of pain. Actually the lasting pain is structured by the series of successive moments. Therefore, I argue that patients with CRPS can live even with unbearable pain by getting rid of the pain in the moment.

This is my question for Professor Frank: for cases in which talking itself makes the patient feel suffering, how can these people make narrations? Also, where would you put "narrative as *shikatagana*" and "narrative as being held" in the three kinds of stories; restitution narrative, chaos narrative and quest narrative, you have put in "*The Wounded Storyteller*." Furthermore, what is the role of a good listener in front of them.

IV. Epilogue

Mrs. A and her family live daily life through their own *ars vivendi* in the face of an illness which is beyond description. What can our society do for them? I also want to continue to think about this big theme.

Thank you for your attention in listening to my speech.