Title	Paradox of diagnosis : The positive effects and limitations of diagnosis in myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS) and fibromyalgia (FM) sufferers
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Citation	Osaka Human Sciences. 5 P.55-P.70
Issue Date	2019-03
Text Version	publisher
URL	https://doi.org/10.18910/71746
DOI	10.18910/71746
rights	
Note	

Osaka Human Sciences, **5**, 55-70
March 2019

PARADOX OF DIAGNOSIS: THE POSITIVE EFFECTS AND LIMITATIONS OF DIAGNOSIS IN MYALGIC ENCEPHALOMYELITIS/CHRONIC FATIGUE SYNDROME (ME/CFS) AND FIBROMYALGIA (FM) SUFFERERS

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Abstract

Diagnosis is a topic of discussion in recent studies on contested illnesses. Without an accurate medical diagnosis, sufferers face the risk that people may think they are malingering or faking. Therefore, receiving a diagnosis can be a critical event for sufferers because it legitimizes their illness. This paper explores how diagnosis impacts the illness experience of myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS) or fibromyalgia (FM) sufferers. The findings can be divided into the positive effects and limitations of diagnosis. Positive effects of diagnosis include achieving relief because of the legitimation of suffering and liberation from guilt; however, diagnosis posits several shortcomings. Often, despite being diagnosed, others fail to recognize the sufferers' condition as a serious disease or as a disease at all. This *paradox of diagnosis* highlights the significance of delegitimizing sufferers' experiences and the vulnerability of legitimate diagnosis.

Key words: contested illnesses, myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS), fibromyalgia (FM), paradox of diagnosis, delegitimation of suffering

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This article is the English translation of the original one "Nojima, N (2017). Paradox of Diagnosis: The Positive Effects and Limitations of Diagnosis in Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS) and Fibromyalgia (FM) Sufferers. *The Japanese Journal of Health and Medical Sociology*, **27**(2), 77–87 (in Japanese)". The publication of its English translation has been permitted by the Japanese Society of Health and Medical Sociology.

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1. Introduction

"Contested illnesses" refer to "illnesses where sufferers claim to have a specific disease that many physicians do not recognize or acknowledge as distinctly medical"[1] (Conrad and Barker, 2010: S70). Myalgic encephalomyelitis/chronic fatigue syndrome, fibromyalgia, irritable bowel syndrome, chemical sensitivity, etc. can be cited as the main examples thereof. What these conditions have in common is that even though the sufferer complains about physical symptoms, no abnormalities are confirmed by an examination. Owing to this, it is believed that tensions arise between a sufferer, who suspects some kind of physical disease or another, and a physician who does not recognize it.

When it comes to such contested illnesses, healthcare providers have noted the increased burdens of primary care physicians, and the increase in the healthcare costs owing to the repeated medical visits by patients, while social-scientific studies have clarified the problems confronted by sufferers. What is shared in the latter case are the effects of an undiagnosed condition of sufferers. Pain that is hard to describe, fatigue that is qualitatively different from overwork, a decline in thinking faculty, abnormal hypersensitivity and so on—when no diagnosis is possible even though a patient is suffering from such symptoms, the illness is not recognized itself, and the patient is suspected of faking an illness or indolence, or a psychological explanation and the name of some mental disease or another is applied (Broom and Woodward, 1996; Dumit, 2006; Nettleton, 2006). The disregard or deprecation of the patient's physical symptoms by healthcare personnel and the people around him or her inevitably drives the patient to engage in doctor shopping, but this not only increases the economic and physical burdens of the patient, but also causes even more suffering to the patient owing to the level of difficulty that is at times equal to or greater than the symptoms insofar as the "reality" of the sufferer is denied (Nojima, 2014). Therefore, it has been pointed that patients feel relief when their illness is acknowledged as a "disease" based on a diagnosis with a disease name, and when they are freed from an "inappropriate" diagnosis name of a mental disorder and the like (Broom and Woodward, 1996; Lillrank, 2003; Sim and Madden, 2008).

However, a diagnosis and a name of the diagnosis do not, in and of themselves, eliminate a patient's pain and suffering (Broom and Woodward, 1996), and the disease name of a contested illness may itself be interpreted as a stigma (Sim and Madden, 2008). When it comes to the downside of such a diagnosis, the difficulty of an undiagnosed condition is all the greater in the case of a contested illness, so it is mentioned relatively infrequently in past studies. Moreover,

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[1] At present, there is no fixed Japanese translation for the English term "contested illnesses." In this paper, based on the situation where a debate has arisen about whether or not something actually exists as a disease, I have translated this term as *ronsouchu no yamai* in Japanese. J. Dumit cites the following five features associated with a contested illness: (1) it is chronic, (2) the cause is unknown, (3) there are various ways to treat it, (4) it has many complications and (5) it arouses legal debates (related to disability benefits) (Dumit, 2006).

even though most such studies have clarified specifically the course leading to the diagnosis and the effects of the diagnosis on the sufferer, they have been inadequate when it comes to examining the temporal fluctuations of the effects of the diagnosis. Furthermore, the effects of the diagnosis on the relationship between the sufferer and others have not been fully studied either. Accordingly, in this paper, I use the narratives provided by persons suffering from myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS) and fibromyalgia (FM), I clarify the effects that a diagnosis has on the sufferer, while paying due attention not only to the point in time when the illness is diagnosed, but also the process after diagnosis and the relationships with other persons.

2. Methodology

2.1. Myalgic Encephalomyelitis/Chronic Fatigue Syndrome and Fibromyalgia

The data used in this paper are the narratives of ME/CFS or FM sufferers obtained based on interviews with them. Before the summary of the data is explained, brief explanations of ME/CFS and FM are provided.

ME, which is known as CFS[2)], is described as a disease characterized by physical and mental fatigue occur after exertion of any sort, and that is accompanied by a strong sense of general exhaustion, mild fever, headache, muscle pain, feeling of weakness, cognitive problems, sleep disorders and so on. FM is described as a systemic chronic pain disorder, and is accompanied by a variety of symptoms including stiffness, weariness, fatigue, sleep disorders, depression, memory disorders, a decline in concentration, etc. The causes of both ME/CFS and FM are unknown, and no methods for treating them have been established, so patients are forced to endure long-term suffering. They are diseases that make it hard for those suffering from them to engage in work and that results in significant problems in their lives, and they do not meet the requirements for the designation as an intractable disease and they are also hard for patients to obtain a disability certificate, so many patients have to endure difficult circumstances both physically and economically.

2.2. Data Collection

Semi-structured interviews were conducted from October 2013 to February 2015 for 31 participants (15 with ME/CFS, 16 with FM) that were recruited through the patient organizations[3)]

[2)] The disease name CFS tends to result in the misunderstanding that it is an accumulation of stress and fatigue, and there are calls for a change of the disease name in various countries for the reason that CFS does not convey the severity of the disease. At present, when the pathological state has not been clarified, it is common for it to be described as ME/CFS or CFS/ME. In this paper, the term ME/CFS, which is adopted in most academic articles, is employed.

[3)] For ME/CFS, I was introduced to participants by relying on the cooperation of the “Japan Myalgic Encephalomyelitis Association, an NPO Corporation,” and for FM, I was introduced to participants by relying on the cooperation of the “Japan Fibromyalgia Support Association, an NPO Corporation.”

Table 1.
Basic attributes of participants

Fictitious name	Gender	Age	Disease	Time from onset to diagnosis	Fictitious name	Gender	Age	Disease	Time from onset to diagnosis	Fictitious name	Gender	Age	Disease	Time from onset to diagnosis
Shimizu	F	40s	ME/CFS	2 years	Ikeda	F	50s	ME/CFS	7 years	Yamaguchi	F	50s	FM	3 years
Suzuki	F	30s	ME/CFS	1 year	Hashimoto	F	40s	ME/CFS	Unknown	Matsumoto	M	30s	FM	11 years
Takahashi	F	50s	ME/CFS	10 years	Yamashita	M	20s	ME/CFS	5 years	Inoue	F	50s	FM	5 years
Hoshi	F	30s	ME/CFS	0.5 years	Ishikawa	F	30s	ME/CFS	12 years	Kimura	F	60s	FM	30 years
Ito	F	30s	ME/CFS	13 years	Maeda	F	40s	ME/CFS	1 year	Hayashi	F	40s	FM	15 years
Yamamoto	M	30s	ME/CFS	1.5 years	Watanabe	F	30s	FM	0.5 months	Saito	F	50s	FM	3 months
Nakamura	F	30s	ME/CFS	3 years	Kato	F	40s	FM	1 year	Sumida	F	50s	FM	0.5 years
Baba	F	30s	ME/CFS	2 years	Ando	M	60s	FM	Unknown	Kurashima	F	40s	FM	20 years
Abe	M	50s	ME/CFS	8 years	Yamada	F	40s	FM	5 years	Nakashima	F	40s	FM	20 years
Mori	F	30s	ME/CFS	4 years	Sasaki	F	20s	FM	2 years	Fujita	F	50s	FM	1.5 years
										Uchimura	F	40s	FM	8 years

as well as introductions of individuals (Table 1). The interviews lasted from one to four hours per participant. Before the interview began, the purpose, contents and methods of the research, the handling of personal information, the public disclosure of the results and so on were explained to the participants, and their written consent was obtained. In addition, they were told that they could withdraw that consent even after the end of the research. The research was conducted with the approval of the Research Ethics Committee, Departments of Sociology and Anthropology, the Graduate School of Human Sciences of Osaka University.

The interviews were conducted in such a manner that the participants could recount as freely as possible their lives from the onset of the disease to the present without any limits imposed on their narratives, at the same time that the interviews were conducted in accordance with the interview guide. The contents of the interview were recorded on an IC recorder and in a notebook with the consent of the participants. All of the narratives provided by sufferers that are used in this paper are extracts from the verbatim records from which the interviews were transcribed.

In this paper, the analysis is focused on the part talked about diagnosis in order to examine the effects of a diagnosis of ME/CFS or FM on the sufferer as well as on the relationships between the sufferer and others. In addition, an analysis is undertaken while due attention is paid to the individual contexts in order to grasp how a sufferer’s experiences before and after diagnosis are related to one another.

3. Analysis

As a result of the analysis, several categories were obtained for the diagnosis, and these can be classified roughly into positive results and negative results. In this paper, the former is called “positive effects of the diagnosis,” while the latter is called “limits of the diagnosis” based on the contents, and both are examined below with representative narratives for each category.

3.1. Positive Effects of Diagnosis

3.1.1. Obtaining a Sense of Relief

The first to be mentioned as a positive effect of diagnosis is a sense of relief. Since it is not possible to specify the abnormality by an examination in the case of ME/CFS or FM, when there is no knowledge about the disease or the existence of the disease is denied and the sufferer encounters a physician, he or she is suspected of faking an illness or of having a mental disease, or is “misdiagnosed.” Even if the sufferer practices self-care or takes the medicines prescribed by the psychiatrist, when his or her condition does not improve, the sufferer will inevitably engage in doctor shopping or no longer be able to carry out his or her routine obligations at work or school. In many instances in this process, the sufferer is regarded suspiciously in various ways by the people around him or her, such as the physician and even family members, and is subjected to inconsiderate comments by them, and thus the sufferer continues to receive a negative assessment from others. For example, Ms. Takahashi recounts as follows such an experience.

> Author: Now, when it comes to the issue of when the (ME/CFS and FM) was found at the same time, how did you feel when you received that disease name?
> Takahashi: Frankly, I was relieved. This was because until that time many people thought that I was lying. I was told that I was malingering. People no longer trusted me. It was precisely because a disease name was finally found that I felt that my condition was being acknowledged. I was relieved.
> Author: When you say that people thought you were lying, to whom specifically are you referring?
> Takahashi: Well, it was my family and the people close to me. After that, at work, and when I met friends, they all thought that.
> Author: Did you explain what you were feeling? That you had these symptoms, and were in a terrible state?
> Takahashi: Yes. But even so I was told by the doctors that they could find nothing wrong with me. And ultimately all trust the doctors.
> Author: I see. So they didin’t trust you because no disease name was found, right?
> Takahashi: Correct. Because there was always the belief that the symptoms themselves were all in my head. Mentally I felt awful about this.

In addition, for Ms. Nakashima the diagnosis of FM was something that aroused joy.

> Nakashima: From the time of the initial diagnosis, the doctor said to me, “Well, you are not wrong. It is fibromyalgia. It is quite bad.” I thought “So I am really suffering from a disease…” In the sense of “Finally.” I almost felt like cooking festive red rice to celebrate it.
> Author: Why were you so happy?
> Nakashima: I was relieved about the name of the disease. It seemed like I was relieved since it could be called what it was without any question after that.

It is not hard to imagine how the uncertain circumstances prior to diagnosis and the negative evaluations of other people received by the patient in the course cause unease and humiliation to the person suffering from the disease. It is precisely for this reason that a diagnosis with a disease name that matches what a sufferer is experiencing with his or her own body results in a huge feeling of relief for such persons, in the sense that what they are complaining about is finally acknowledged by a corresponding diagnosis.

3.1.2. Legitimation of Suffering

Obtaining a sense of relief due to a diagnosis amounts to nothing more than the fact that a sufferer’s illness has been recognized as a disease by a physician, rather than being recognized as such by anyone else than anyone other than the patient himself or herself. A. Lillrank, who focuses on the narratives of patients afflicted with lower back pain, notes with reference to J.E. Jackson that pain is legitimized (medically), and this is transformed to the sufferer himself or herself and to a part of his or her identity, and results in recovery of his or her social status as an “ordinary citizen” (Lillirank, 203: 1053). To put it the other way round, an illness that has not been medically recognized makes the sufferer’s social status uncertain or results in a loss of social status, and this situation subjects the sufferer to a crisis that threatens himself or herself and his or her identity.

For the sufferers as well, precisely because the diagnosis of ME/CFS or FM is the turning point when the suffering about which the person in question had been called “selfish” or “indolent” to that point in time is recognized as a legitimate “disease” based on a medical authority, the sufferers feel the sense of relief observed in the preceding section. Moreover, being acknowledged as a “disease” medically means that the person is allowed to be ill as a socially permitted exceptional situation. The following narrative of Ms. Maeda exhibits very well the legitimizing function of diagnosis.

> Maeda: I had thought if it was good that the disease was discovered after one year. If I think about this after the fact, to that day, it took me as long as one year. But I was somehow happy, you know? Strange talk. It is strange to say so. It is an illness. Finally, I learned that I had some kind of illness. Perhaps I should say I was relieved? I thought well now, I can finally write

> and submit to my company a medical certificate with the exact disease name. Naturally, I was on leave the entire time. During that period, I did not go to my company a single time.

In addition, there is the case of Ms. Kimura, who visited numerous hospitals over a period of approximately 30 years until she was diagnosed with FM, and who said about the experience, “Somehow ultimately I had been going to these hospitals all along with an incomprehensible disease.” Ms. Kimura relates as follows the joy that she felt when the fact that she had a disease was proven by the diagnosis of FM.

> Kimura: I was overjoyed. Until now I had been treated as an oddball. Even though there was no reason, I was saying that I was in pain, and I thought I was going to die. It was pain that I could no longer even scrawl. It was an illness that people rarely suffered from. And for that reason I was partly rendered as a “nutcase.” People told me I was lying. They said that because I did not want to move. I heard the same from my own children. And I heard the same stuff from my parents and my siblings too. […] But then the name of the disease was confirmed. And when I was told this, I could say that I have a disease. It was joy from being able to say that I have a real disease. I remember that I was involuntarily in tears.

But when it comes to such legitimation of suffering, it is not the case that just because a sufferer has been found to have a “disease” that he or she is not questioned about the contents thereof. People suffering from ME/CFS or FM often diagnosed with any other disease prior to receiving a diagnosis of ME/CFS or FM. There is a tendency to treat such people among others as if they have a mental illness or psychological problem. Not only does the name of the mental illness and the explanation of conformity with this not match the sufferer’s physical feelings, it is also hard for them to accept as something that invalidates those physical symptoms[4]. In spite of this, when another disease name is not given, the sufferer either reluctantly undergoes treatment as a patient with mental illness, or has no choice, but to engage in repeated doctor shopping. A sufferer who has experienced such a process tends to describe the diagnosis of ME/CFS or FM as a positive event. It derives from the *reality of the body* of the sufferer whereby his or her physical symptoms cannot be properly explained by interpreting them as mental illness or a psychological problem, rather than the prejudice against mental illness.

3.1.3. Liberation from Self-blame

According to P. Conrad and J. W. Schneider, who discuss the medicalization of deviations,

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[4] For example, Ms. Ito was diagnosed with “depressed state” before she received a definite diagnosis of ME/CFS, and spent many years going to the psychiatry department at the hospital, but according to her, she had doubts about such a diagnosis all along. “I felt that my own symptoms were not fully expressed by just ‘depressed state.’ So to be honest, I thought it was a bit different. Well, it is true that I was in a depressed state, but I felt that not all of my own condition could be expressed by just that words. I felt very strongly about this. Yes.”

"Medicalization is related to a longtime *humanitarian* trend in the conception and control of deviation" (Conrad and Schneider, 1992 = 2003: 466, sic). They say, for example, medicalized alcoholism is no longer regarded as something caused by the sin or moral weakness of the person suffering from it[5]. The "brighter side" of such medicalization is that the positive result of liberation from self-blame occurs due to a diagnosis, which is the phase of medicalization, in persons suffering from ME/CFS or FM. For example, Ms. Ito recounts the background of her release from self-blame owing to a diagnosis of the disease name as follows.

> Ito: Due to the fact that a name was given to the disease, the fact that I was somehow, of my own will, at home, it was disgraceful (it is what is thought), you know? That was the saddest thing for me. To be regarded as a disgrace by my own family. And of course everyone in the neighborhood also knew that I was at home all the time. Of course, they know that. And my mother told me, there are rumors going around about you. My family was also pestered about this; everyone in it. It became the talk of the town. There is a person who stays at home for some unknown reason. Whether she is sick (no one knows). I think that there is still no one in the neighborhood who believes that I have a disease. Compared to the neighborhood, though such a comparison may be a bit odd. Anyway, no one thinks I am sick.
> Author: I see. When a name was given for the disease, since you were at home with the disease….
> Ito: Yes. The reason for it was made clear. Just the reason. The reason, or the reason is me that my physical state was poor and that is why I was (at home) due to this. It is exactly right. I want to go out, to outside. Honestly, I wanted to go to school and study things. I wanted to have friends, I think. This is not something that I am doing of my own volition, honestly. But in spite of that, when no name is given to the disease people end up thinking that it is something involving the person in question. They regard that I am at home all the time as a way of life. […] Well, it became a long story, but it may protect from the eyes from the public and almost such things. I had not done anything bad myself. This is the very meaning of a name was given to the disease. That was how I thought about it.

Although Ms. Ito was not at home of her own volition, that is how it was regarded by the people around her. During the time when a diagnosis of ME/CFS could not be obtained, Ms. Ito was tormented by pressure that made her bear the responsibility for such a situation. However, once a disease name was given, the fact that there was a "legitimate" reason why she could not leave her home was substantiated, and she was able to believe that "I had not done anything bad

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[5] However, Conrad and Schneider are dubious about the tendency to assume that a certain problem is no longer a moral problem once it has been defined medically.

myself.[6]" Many of the participants offered similar narratives. Let us now examine the narrative of one of them, Ms. Baba:

> Author: I think that it took about two years for you to be diagnosed. What did you think when you were told that it was CFS?
>
> Baba: Well, when I learned the cause, I had a relieved feeling, you know? And then a bit later, I thought it is so, then I will not be cured, I mean my condition is incurable. It seems that I thought afterward about the fact that there is no clear treatment method. Up until then I had been blamed somewhat by those around me. I was told that I had some sort of mental problem. And I think I was relieved when I learned that to the contrary there was a physical cause, you know?
>
> Author: As far as being blamed by those around you is concerned, was something actually said to you by those around you?
>
> Baba: Yes. I was told that I was malingering. That I was slovenly. I heard such things from my family as well. And I myself wondered why I could not do things even though I needed to do them. I blamed myself excessively as well. It was the same when I went to school. I could not do as well as the other students.

Ms. Baba was at that time living a minimal existence physically amidst fatigue whose cause was unknown. She was evaluated as "indolent" and "slovenly" by the people around her, and ended up blaming herself for the fact that she was unable to do what was to be done with school assignments and so on, but she was released from self-blame due to the diagnosis of ME/CFS. For Ms. Baba, a diagnosis with a disease name meant not only that a disease had been *found*, but also that the reason why she could not move her body the way that she wanted did not lie in her own volition or mental state, and this was experienced as *proof* that the cause lay in her *body*, which could not do the things that she wanted it to do.

From such narratives, we can see that a diagnosis of ME/CFS or FM releases the sufferer from self-blame since it proves that his or her condition is not something due to a moral or mental issue, but rather due to something that is medical or physical in nature.

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[6] The person receiving the benefit of a disease name diagnosis that guarantees a "legitimate" reason is not just the sufferer himself or herself. The following narrative of Ms. Ito suggests that her family was also saved when a name was given to her disease. "It was because this disease was vague. Because it was called a mental problem, this might be interpreted as a problem with the way I was raised as a child. Since I saw quite a lot how (my mother) blamed herself for the way in which she had raised [me], she may have felt disgrace about that. It was common for everyone around us to think that it was a problem with the way I was raised. […] I had not been seen lately and everyone asked what was wrong. Surely enough, suddenly when I stayed in the house, they thought I refused to go to school or used domestic violence. And no matter how many times it was explained to them, there was no one who understood my situation. So this became a matter of disgrace for the family…"

3.2. Limits of Diagnosis

3.2.1. "If you have a complaint, I will listen to it": Illness Experience That is Damaged

Many of those suffering from ME/CFS or FM experience humiliation, such as being suspected of faking an illness or indolence by the people around them, until the point when a definite diagnosis is reached. Such a negative evaluation by others may at first sight appear to originate in the fact that the condition has not been diagnosed as a (physical) disease. As it happens, for sufferers, a diagnosis of ME/CFS or FM is received as proof that they are suffering from a (physical) disease, and it becomes the turning point for obtaining mental stability. However, when it comes to a sufferer's relationships with other people, a diagnosis of ME/CFS or FM does not necessarily have positive effects. For example, when Ms. Suzuki consulted a public health nurse about whether or not she could receive welfare services after she received a definite diagnosis of ME/CFS, she was shocked when that person replied, "If you have a complaint, I will listen to it."

> Suzuki: … I had [the public health nurse] visit me several times, but then finally, I was told "There is nothing that I can do, but if you have a complaint, I will listen to it." I was a bit shocked by those words. I thought that what we were presenting about our illness sounded like nothing more than complaining. Even though I had consulted many times… Public health nurses said that they had the stance of just coming to hear complaints. In the discussion, it was told that my condition did not require welfare services.
> Author: I see, I see. So that is how it appeared to that person's eyes?
> Suzuki: The appearance was important. At that time I was not still in bed when seeing people. I had the feeling that I would sit and talk to people at the minimum.
> Author: You were pushing yourself too hard, weren't you?
> Suzuki: Yes, I was. I was pushing myself too hard, but that did not convey to her. Even if I had conveyed this with words, I could not get her to believe it.

What is important here is that Ms. Suzuki had explained her own condition after telling the public health nurse the disease name of ME/CFS. It was hard for Ms. Suzuki to even sit, but she pushed herself since she felt it would not do to be impolite and sat for the talk with the public health nurse. However, when Ms. Suzuki, who collapses from even the slightest amount of housework, tried to describe her difficulty in living, it sounded like "complaining" to the public health nurse. It seems that for the public health nurse the diagnosis of ME/CFS and Ms. Suzuki's explanation did not to be considered more than Ms. Suzuki's appearance when she was seated and talking.

The reason why the severity of the disease is not conveyed in this manner is not due to the fact that the other person is not someone close to the sufferer. There are many cases where even family members, who might be expected to know/observe how a person with such a disease is actually suffering on a daily basis, do not regard ME/CFS or FM as a severe illness. For example, there is the case of Ms. Inoue, who frequently talked about her condition with her older sister. Here is her narrative of what happened when she was diagnosed with FM.

> Inoue: Since she asked me, "What is it?", when I told her "I have learned what my illness is," I told her, "Fibromyalgia," and she asked "Is there a cure for it?" And I responded, "There is still no way to treat it." And then when I said "Even so, it is a disease from which I am not going to die anytime soon," she replied, "Oh, you won't die. Well, then it is nothing serious." And I was shocked at this response.

Ms. Inoue's elder sister was aware of the fact that Ms. Inoue had been hospitalized repeatedly, but she did not recognize such a condition as a disease. In this process, the diagnosis of FM was an opportunity for the elder sister to reinterpret Ms. Inoue's condition as a disease, but instead she assumed that FM was a disease "that was nothing serious" based on a single point, that it is not a "disease that people die from."

From the narratives provided above, we can see that the severity of ME/CFS and FM is not conveyed to the people around the sufferer by just the fact that it has been diagnosed. In other words, regardless of the disease being diagnosed or not, the assessment of the people around the sufferer about the suffering itself remained low. In this manner, despite the fact sufferers are diagnosed and exhibiting all the symptoms, it can be said that their illness experiences are damaged in the same manner as before the diagnosis insofar as the reality of the sufferers is not taken seriously when it comes to the actual state that is not conveyed to others.

3.2.2. "There is no such disease": Non-existence of a Disease Expressed by the Disease Name

In the preceding section, we confirmed that the illness was not taken to be something serious by other people, even after a diagnosis with a disease name was made, and that the illness experience by those suffering from ME/CFS or FM is damaged. Such a state of affairs arouses great mental torment in sufferers akin to what they experienced prior to diagnosis, but just the fact that their condition has been recognized as a "disease" might be good. That said, this is because there are many cases in which their condition is not regarded as a disease despite the fact that they are telling others that they have been diagnosed. For example, Ms. Kimura recounts in a mortified manner how, when she experienced sharp pain at her parent's home, she was told by her younger sister, who prided herself on the fact that "There is no one who knows more about fibromyalgia than I do", that "if you think it is not painful, then it is not painful."

> Kimura: Since I was in pain at my parent's home, [I thought that] I was at the point where I was going to die. And my younger sister said "if you think it is painful, then it is painful." She said, "This is because even though your brain is exhibiting an abnormal reaction, it is different from a disease. Because you think it is painful, painful, painful, it just becomes painful. Take

> a deep breath. If you think it is not painful, then it is not painful. You are OK. Because I know about this disease." I thought this was nonsense, but I could not say anything to rebut it. I know the pain will subside after one or two days. I have endured this pain for more than 30 years now, and I know all the ways there are to breathe to endure it. It is not as simple as my sister thinks. So my younger sister had a smattering of knowledge about it, and she said this thinking that she knew all about my disease, and this made me incredibly sad. I was so sad that I thought about cutting off my ties to my own younger sister over this.

"If you think it is not painful, then it is not painful." These words from Ms. Inoue's younger sister mean the same thing as "It is all in your head," responses that are frequently heard by those suffering from contested illnesses (Lillrank, 2003). Such responses mean that symptoms that are invisible to the eye, such as pain and fatigue, all amount to nothing more than a product to the sufferer's imagination. Ms. Kimura's younger sister, who supposedly "has understanding" about FM, did not actually regard FM as a disease, and interpreted the intolerable pain suffered by Ms. Kimura as a failure of image control by Ms. Kimura.

Mr. Yamamoto, who has ME/CFS, has had the same experience as Ms. Kimura. He relates that owing to the fact that the disease was diagnosed, "I myself was able (to understand, and the number of people around me such as Mr. X (who was suffering from the same disease) also increased, but "I could not explain it to my family at all." Although Mr. Yamamoto handled household chores and work despite the fact that he could not move as he wanted to, he says that his family interpreted his symptoms as "a problem with my feelings." When he was dead tired at home, his family members censured him for faking an illness because he could get out of housework that way, and said such things as "You are just loafing around." His family, which has expert knowledge, said, "You say it is medical, but that has not been proven," and denied the existence of a disease by bringing up the fact that no biomarkers (indexes that are pathophysiologically substantiated, and that measure whether or not there is a disease and its progress, the reactivity to treatment and so on) exist. From Mr. Yamamoto's narrative, we can see that, although diagnosis with the disease name of ME/CFS was helpful in allowing Mr. Yamamoto to understand the disease himself and having ties with other people suffering from the same disease as well as deepening mutual understanding, it still could not serve as the grounds for explaining the illness in his relationships with his family members, the people closest to him.

In the case of Ms. Mori, despite the fact that she conveyed the fact that ME/CFS had been listed in the ICD, the International Classification of Diseases, and showed the grounds of being a "legitimate" disease, the existence of any disease has been *clearly* denied. When Ms. Mori went to the ward office for a consultation about a disability pension after the diagnosis of ME/CFS, she was still handled by people who were not in charge of that, and the end result was that one of those people told her "There is no such disease," and both astonishment and shock welled up in Ms. Mori.

> Mori: Well, “Oh, someone else is in charge of that,” which I heard from about four people. And then I consulted with the fourth person, whom I thought was an earnest woman who looked like she was very intelligent. I said that there is a disease called chronic fatigue syndrome. And within this, the number of ICD is applied, and there are also results whereby sufferers are assessed as having grade 2 and 3 and so on. And while I think it must be difficult, when I said that I wanted for the time being to receive a form and look at it, I was told “There is no such disease.” She snapped at me. I was stunned.
> Author: How old was the person in question?
> Mori: She was in her late 50s. She seemed to be a spinster. But she looked quite earnest. At the outset she was extremely polite to me. So I thought, if anyone can understand this, it will be her. I thought she would be more reliable than the other people before her. But just when I thought that I had finally found someone who could understand what I was talking about, I was told “There is no such disease.” And this despite the fact that there most definitely is, as is indicated in the classification by ICD. And in spite of the fact that (disability pensions) are being provided (to persons with ME/CFS), why would you (that woman) say such a thing to me? It really ticked me off, and I am the kind of person who rarely gets angry (laughs).

In other words, Ms. Mori tried to explain to an official of the ward office based on the “objective fact” that it is described in the ICD rather than her personal situation that there are various difficulties in daily life. However, despite Ms. Mori presented such “fact,” the official not only did not listen to what Ms. Mori said, she denied the existence of the disease itself. “There is no such disease.” Ms. Mori’s appeal was invalidated by this dismissive response, and no further dialogue was possible after that.

What the participants in this study had experienced, just when they thought that they could finally explain that they had been diagnosed with ME/CFS or FM and that it is a disease, was the uselessness of a disease name in their interactions with others. That is to say, the suffering will continue to be trivialized by others even after the diagnosis, and in some cases the very existence of the disease itself is denied.

4. The Paradox of Diagnosis: The Delegitimation of Suffering by Others around the Sufferers

In this paper, I have examined the effects of a diagnosis of ME/CFS or FM on sufferers by discussing separately the positive effects and limits of such a diagnosis. The positive effects and limits of such a diagnosis can be summarized as follows: First of all, the positive effects of the diagnosis, which were examined in Section 3.1 above, occurred first and last in the sufferers themselves, but the limits of the diagnosis, which were examined in Section 3.2, occurred in the relationships between the sufferers and others. In addition, in 3.1 the disease name of ME/CFS or FM was welcomed by the sufferers as something that caused their own (physical) symptoms, that is as something that expressed the actual existence of a disease, but in 3.2 we confirmed that almost no positive effects due to the disease name occur between the sufferer and others, or that paradoxically the disease name ends up expressing the non-existence of the disease. In other words, the positive effects of a diagnosis of ME/CFS or FM that are manifested in individual sufferers reach their limit in situations involving others, and the *paradox of diagnosis* whereby a disease name that expresses the actual existence of a disease expresses the non-existence of the disease occurs7). The findings of this study, which proposes the limits of diagnosis and the way in which it is expressed as the paradox of diagnosis, raises the need to fully examine the positive effects of diagnosis. In other words, the need to identify the positive effects of diagnosis by taking into account the temporal limitations as well as the limitations in a sufferer's relationships with others, at a time when the majority of studies about contested illnesses stress the positive effects of diagnosis8).

Based on the discussion by A. Kleinman, the paradox of diagnosis is a situation that can be termed delegitimation of suffering by the people around the sufferer. In Kleinman's cases, the symptoms of persons suffering from chronic pain are regarded as excessive demands, a psychological problem or an exaggeration of stress by physicians. Thus, the legitimacy of the experience of illness is doubted implicitly or explicitly, and the stigma of a mental illness or faking a disease is imposed on the sufferer. Since it is not possible to respond to the questions of "Why is the pain occurring?" and "What meaning does the pain have?" based on the biomedical approach, the expression of suffering by the sufferers, who want an explanation based on the origins and mechanisms of the disease, prompts its delegitimation by physicians, who regard it as intractable (Kleinman, 1995: 133).

Compared to such a delegitimation of suffering by physicians, what was occurring in the cases examined in this paper is delegitimation by the persons around the sufferers. In general, a sufferer who obtains a diagnosis with a disease name is accorded the status of a "patient," and is exempt from various duties based on social acceptance of his or her condition and allowed to devote himself or herself to his or her disease. But a diagnosis of ME/CFS or FM does not necessarily guarantee that the sufferer will be regarded as a "patient" in his or her relations with others, and also does not serve as a reason for him or her being excused from routine obligations. In other words, the suffering of ME/CFS or FM people is legitimized once they have been diagnosed, but

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7) With regard to a disease name expressing the non-existence of a disease, S. Madden and J. Sim mention that a diagnosis of FM is an "empty diagnosis." "Although the diagnosis validates the illness experience, it has no meaning per se." (Madden and Sim, 2006: 2967). The uncertainty of a sufferer from FM, who has been tormented ever since the disease's onset and who wonders what to do given that there is no way even to express his or her own condition, is replaced by a new uncertainty due to the diagnosis.

8) M. Undeland and K. Malterud urge caution with respect to the temporal limitations of the positive effects of a diagnosis. They note that when viewed over the long term, a diagnosis with the disease name FM does not ensure the status of the patient, and does not generate the "common language" that can explain the illness in various social circumstances (Undeland and Malterud, 2007).

it is delegitimized by others, who do not believe in the legitimacy of the diagnosis. This suggests that the social status of a sufferer is not secured solely by the fact that he or she has been diagnosed with these diseases. In other words, it suggests the vulnerability of the legitimating function of the diagnosis itself.

5. Conclusion

The paradox of diagnosis, wherein a diagnosis with a disease name that legitimates the suffering and indicates that the disease really exists expresses the non-existence of the disease in the sufferer's relationships with others, is the same as before diagnosis insofar as it arouses mental distress in the sufferer, but before diagnosis there was the *hope* that if only the disease were diagnosed the sufferer would be able to explain it to others. However, the sufferer is confronted by a dilemma in a situation where his or her condition is not regarded as a disease, even when he or she explains it based on diagnosed facts9) (if the sufferer does not say that he or she has a disease, he or she will be suspected of laziness or faking an illness, but even if the sufferer does tell others that it is ME/CFS or FM, he or she might still be suspected of laziness or faking an illness, or the very existence of such a disease is denied). Various factors, such as an inadequacy of social awareness, the non-existence of biomarkers and the invisibility of the symptoms, may lie in the background against which such a paradox and dilemma occur. It will be necessary to focus on the background against which the paradox of diagnosis arises, and to elucidate the mechanisms of the paradox, which cannot be reduced to just communication between sufferers and others. Then, considering a diagnosis with a disease name does not gurantee the actual existence of a disease in the sufferer's relationships with others, we need to study conditions about how the *social reality* of the disease should be ensured in our society.

Acknowledgements

The author would like to thank all those who cooperated in this research. This study received funding from a 2013 fiscal year research promotion grant from the Institute for Research on Household Economics as well as from a 2014 fiscal JSPS KAKENHI (Grant Number 14J00416).

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9) C. Lonardi argues that an "identity paradox" occurs for people with chronic headaches no matter how they try passing through life with it. When the social image of a disease is inadequate, the sufferer will have to behave like a normal person unless he or she disclose his or her illness, and he or she will be exhausted; however, if the sufferer disclose everything, it is not understood by others, so he or she confronts a dilemma (Lonardi, 2007).

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