PARADOX OF DIAGNOSIS

The positive effects and the limits of diagnosis in ME/CFS and FM patients

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OUTLINE

• Introduction
• Methods
• Results
  - the positive effects of diagnosis
  - the limits of diagnosis
• Conclusion
INTRODUCTION
• Sociology of diagnosis


“diagnosis as a kind of focal point where numerous interests, anxieties, values, knowledges, practices and other factors merge and coverage”

(Jutel and Nettleton 2011)

• The sociology of illness experience and illness narratives

(Bury 1982; Charmaz 1983; Williams 1984; Frank 1995)

- diagnostic experience: how patients experience diagnosis?
Diagnosis is a critical phase or event for patients with contested illness or medically unexplained symptoms (MUS).

They are termed "medically unexplained symptoms" when doctors cannot find any disease or problem with the body that would otherwise account for the symptoms.

Ex. ME/CFS, FM, MCS, IBS, RSI, unnamed back pain, etc.
“The pursuit of diagnosis emerges as one of the most pressing issues identified by people who have the condition.” (Jutel 2011: 78)

Without a diagnosis, there is a risk that sufferers could be denied social recognition of their suffering and blamed for pretending to be ill.

(Dumit 2006; Broom and Woodward 1996; Lillrank 2003; Jackson 2000)
IN THE CASE OF MUS, RECEIVING A DIAGNOSIS...

• is a **relief**: legitimizes patient’s illness
• can enable people to **access information**
• removes an “inappropriate” label
  ex. psychiatric diagnosis
• gives a **cognitive identity**

  (Broom and Woodward 1996; Dumit 2006; Hadler 1996; Nettleton 2006; Jutel 2011)
Patient with MUS is thought to be a hard case to deal with by doctors (Okada 2013).

Medical studies on MUS in Japan usually include those on disease mechanism, possible clinical biomarkers, or the way to treat patients with general malaise.

There are very few sociological studies from the patients’ view point.

There is no study about the impact of the MUS diagnosis on the patients and families.

I would like to focus on...

How do patients and people around take the diagnosis of MUS?

in the case of ME/CFS and FM
ME/CFS

- Debilitating and complex disorder characterized by profound fatigue that is not improved by bed rest and that may be worsened by physical or mental activity.
  (http://www.cdc.gov/cfs/)

- Estimated number of patients in Japan
  360000 potential patients (about 0.3% of the population)
  (Kuratsune 2012: 73)
FM

• A disorder of unknown etiology characterized by widespread pain, abnormal pain processing, sleep disturbance, fatigue and often psychological distress.

(http://www.cdc.gov/arthritis/basics/fibromyalgia.htm)

• Estimated number of patients in Japan
  200 million potential patients (about 1.7% of the population)

(MHLW research group 2005)
METHODS
DATA COLLECTION AND ANALYSIS

- Sample
  17 participants (ME/CFS: 8, FM: 9)
- Procedures
  - semi-structured interview
- Analysis
  - Bottom-up qualitative analysis (basically followed GTA)
  - Used especially focused coding and process coding (Saldaña 2012)
# PARTICIPANTS

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<th>Demographics</th>
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<td>Gender (Female)</td>
<td>14 (82%)</td>
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<tr>
<td>Gender (Male)</td>
<td>3 (18%)</td>
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<tr>
<td>Age (range)</td>
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* Not include divorce and bereavement

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<th>Education and Employment</th>
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<td>Bachelor or above</td>
<td>7 (41%)</td>
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<tr>
<td>Unemployed</td>
<td>14 (82%)</td>
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RESULTS
POSITIVE EFFECTS OF DIAGNOSIS
LIBERATION FROM GUILT-SENSE

• Receiving a diagnosis liberate patients from their guilt-sense.

“I did nothing wrong. That’s the meaning of obtaining a disease name”. (Michiko, ME/CFS)

“Yes, I could understand the cause of illness, then I felt like a relief. (…) Till then, some around me had been blaming me. They said that it was mental. So, I think, I was relieved when it turned out there was a physical cause, yes”. (Akemi, ME/CFS)
Diagnosis of ME/CFS or FM validates patients’ suffering as a physical disease or the actually existing state.

“Conversely, in a weird way, I felt somewhat relieved. I have to say… I finally found it (ME/CFS). Many doctors often told me that it (my suffering) was up to just how you felt”. (Yuji, ME/CFS)

“I felt relieved. Well, till then, well I was often suspected as a liar. Well, people often told me that I was just idle or... I had been feeling myself not trusted by anyone (before getting the diagnosis). So, when I received the diagnosis, I felt I was recognized and was relieved”. (Ryoko, ME/CFS)
ACCESS TO CONCRETE INFORMATION

• It was not until they received an appropriate diagnosis that patients are able to access concrete information.

  Ex. treatment, doctor, hospital, clinical trial, medical research, patient organization
LIMITS OF DIAGNOSIS
There are only symptomatic treatments. Getting a diagnosis has no impact on treatment.

“I was relieved because it was not a mortal disease. However, there is no cure. And also nothing has changed in terms of treatment. I received the same pain killer as I had before the diagnosis. So, there was no use of getting the disease name.” (Aya, FM)

“According to the internet, no effective treatment has been established. The diagnosis itself says, well, it is a disease, and I have the symptoms. However, (…) unlike multiple sclerosis it is not a definite disease. I’ve heard that the cause differs from person to person. So I realized that the only way is to deal with it by myself”. (Yoko, FM)
“When I told my sister that I received the diagnosis, she asked me what it was. Then, I told her it was fibromyalgia. After that, she asked me how to cure it, I answered that there was no way to cure. Yes. “But, for the time being, it is not a disease to kill me soon,” I told her. And then, “Oh, you are not going to die. So, it’s not serious,” she told me.” (Kyoko, FM)
• Diagnosis itself does not prove the existence of disease.

“When I laid breathing very feebly because of pain, ‘Sister, you have a pain because you think you have a pain. It is not a disease but an abnormal reaction of the brain. (…),’ my sister said to me.” (Takako, FM)
CONCLUSION
Diagnosis of ME/CFS or FM brings patients positive effects crucially.

For the patients, a diagnosis is not only the event that they just receive the name for their suffering from a doctor.

But also the event they may become able to explain that their suffering is physical disease and remove an inappropriate meaning such as malingering, idleness, and mental disease from them.
PARADOX OF DIAGNOSIS

- Diagnosis of ME/CFS or FM makes others recognize patients’ condition not as a serious disease or not as a disease.
- For patients, ME/CFS or FM is used as a medical category.
- For others, however, ME/CFS or FM diagnosis is a decent disease or even a disease.
- Diagnosis of ME/CFS or FM brings patients paradoxical situation that they can not receive the social recognition even though they receive a diagnosis which ensures the legitimacy of their suffering at first.
FUTURE WORK

• Differences between ME/CFS and FM

• What prevents medical diagnosis from legitimizing the patient’s suffering?
  - Just lacking of social recognition?
  - Because biomarker has not been discovered yet?
  - Stigmatized social image of mental disease or a disease related to “the mental”?

• Interviewing the people around the patient
ACKNOWLEDGEMENT

- This study is supported by The Institute for Research on Household Economics.

- Special thanks goes to participants who took an interview and all the people who cooperate with this study.

Thank you very much for your attention!