

Place and Relationship in Which Narratives of Illness are Produced: Stories from the Multiple Self

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1. Chronic disease and narratives of illness

I specifically focus on the psychological care of patients with chronic diseases. I argue that we all have some experience of illness, in a sense that everyone got sick at least once in his or her lifetime. From the medical point of view so far most of previous studies on illness only aimed to diagnose and to remove the cause of the disease because these studies believe that removing the cause of an illness would lead to a huge improvement in terms of symptoms and behaviors. Being ill has been considered as “an unusual state” for a long time. However, for the patients with chronic diseases who do not have the prospect of “complete recovery,” being ill is an everyday routine, and a part of their life. Therefore, studies of illness must be focused on the meanings of life of the people who have to live with chronic disease.

Kleinman (1988) clearly differentiates the terms “illness” and “disease.” According to him “disease” designates a medical-biological problem from a practitioner’s perspective, while “illness” refers to how the sick person, members of his or her family, and larger social networks perceive, live with, and respond to the symptoms and disability. Furthermore, in the practitioner’s act of recasting illness as disease, according to Kleinman, something essential to the experience of chronic disease is lost: therefore “illness” becomes illegitimated for clinical concern and does not receive medical intervention. Frank (1995) also argues that more is involved in ill people’s experiences than the medical story can tell, and emphasizes the importance of reclaiming their own colonized bodies, illness experience, and voices. These theories emphasize the significance of ill people’s “voices,” and serious issues related to the supports of the patients and their existence, which are linked to maintain the social system (Hidaka, 2011).

2. The experience of IBD patients

The disease, called IBD (Inflammatory bowel disease), is the main subject of my research. IBD consists of two major subcategories: ulcerative colitis and Crohn’s disease. These two are categorized as Special Chronic Diseases by the Japanese government. These are chronic, lifelong illness with no identified distinct causes and no fundamental treatment. The main symptoms are severe abdominal pain, diarrhea (with rectal bleeding), fever, weariness, anemia,

etc..., and it may lead various kinds of complications.

IBD patients have difficulty in daily tasks such as eating and excreting. It may cause repetitive hospitalizations which hinder their social activities. Moreover, the onset age peaks at the teens and the 20s, which, therefore, forces them to struggle in dealing with significant life events such as entering school and finding jobs. Major symptoms of this disease sound familiar to even healthy people, however it is often called "silent illness." The pain that the patients experienced tends to be misunderstood as "less severe". However the quality of the pain is completely different from that experienced by normal people. Therefore, this underestimate creates more misery. More concretely, secondary pain is said to be added to the original one by a vicious circle of stress, deteriorated physiological symptoms, and psychological sufferings.

I carried out earlier an interview survey to six IBD patients. The analysis of those informants' responses suggests that there are certain issues which the patients have some difficulty in disclosing due to the delicate characteristics of the symptoms. That drew the following conclusion: this uneasiness prevents them from opening up to society and gaining acceptance, it actually isn't easy for people to clearly understand this vague disease, which represses patients' motivation to speak up. The ignorance in which others are makes patients hold the psychological stress by themselves, and may aggravate the malady.

3. Purpose

This study aimed to put emphasis more on the place in which narratives are produced and on the relationship between the interviewees and the interviewer rather than on the contents of the interviewees' story, and on what was the significance of narrative for an informant. Let's take some examples of the conversation with Ms. M.

4. The relationship in an interview – a talk of Ms. M

-Ms. M's profile

Today I would like to tell a story of an interview with a female patient called M. Before beginning, I should give some information on her. Ms. M is one of the six informants I mentioned above, who suffers from an ulcerative colitis. At the time of the interview, she was in her middle 20s. Her physiological illness had been lasting for one and a half years. She did not have a job, and lived with her parents and sister. She was hospitalized when the symptoms came up. After being discharged from the hospital, she got medication as an outpatient, and was on a diet in Home Therapy. I should also tell you a fact that she suddenly fell into a depression at the time of her first hospitalization, and started a psychiatric treatment along with her internal care.

-Meeting with Ms. M

To talk about Ms. M, I should first explain how we met and talk about myself first. Five out of the six informants were those who I met at an event for IBD Patients Association, and I got permission to interview them. The only exception was her. She was not at the event. Instead, her mother attended the event for her. She told me, “my daughter rarely goes outside, but she might want to talk with a person like you who is of the same age.” After then, Ms. M contacted with me saying that she agreed to have an interview, and we decided to meet. I met her for the first time at the moment of the interview. The interviews were held twice for one hour each, considering her physical and mental condition.

-The interviewer’s information

In order to talk of the interview with Ms. M in terms of relationship, sharing information about the interviewer – i.e. me – is needed. I have been dealing with this issue from various perspectives, however, the most important thing I would like to confirm here is that I am a person suffering from IBD. It was the first contact with Ms. M, but I am sure that she knew that I also was a patient of the disease.

-Between fellow patients (peers)

In the interview, something interesting occurred: Ms. M, not the interviewer but the interviewee, asked me a lot of questions. Of course she understood that this setting was for a research purpose, and we had not yet broken the “flow” of normal interviews (the interviewer asks and the interviewee answers) when she suddenly started asking questions while we were talking about the medical history.

<Data A>

M: Now you go to X (a hospital name)?

Interviewer (me): Yes.

M: Have you ever hospitalized?

Interviewer: I stay there a couple of times in a year.

M: Did you get sick after you got into the university?

Interviewer: During the second year of my Master’s course.

M: Are you taking B (a drug name) instead of A (a drug name) now?

Interviewer: Now I’m using C (a drug name) which was recently certified. This drug is composed of the same elements as B which however had severe side effects on me.

That was the first questions which Ms. M first asked me in the interview. I intended to only ask her questions; however I released my own personal information a little, being

confused and impatient to react to such sudden questions. To tell the truth, it was the first experience for me to have an official interview. In that scene, Ms. M regarded the interviewer as a peer, and tried to get more information from me. It might be natural that she wanted to know my experience as well as I needed to know her.

Moreover, a unique relationship appeared in the dialogue in which we expressed the actual names of the hospital and medication. For the relationship between asking and replying depends on how much an interviewer and an interviewee know each other. People have a tendency to explain as clearly as possible, in order to make the listeners understand, when they do not know each other. However, there were no such moments during this interview.

-Between female fellows in the same age group

There can be many reasons for people to be curious about others' life styles, especially we want to know people's opinion about issues from which we are suffering.

<Data B>

M: Are you preparing meals by yourself?

Interviewer: Yes, I am.

M: Did your parents help you when you first got sick?

Interviewer: No, I was already living by myself here.

In addition, "Do you ask your parents for help when your condition got worse?", "Is your husband working in the same field (helping profession)?", and "Does he provide all the living expenses?" , she asked such questions.

In the interview Ms. M repeatedly told me that she believes that she has become a huge burden in her parents' life for food, fees, and mental support, she is afraid in relation to her future independence from her parents, wondering whether she could manage everything by herself. She also has hard time getting understandings even from her family and friends. The questions she asked probably came out from such worries. She asked questions not only because we are sharing the same suffering, but also because we are in the same age and gender group.

-Between an interviewer and an interviewee

On the other hand, there was also a scene where the informant might be conscious of a role as an interviewee. The following conversations suggest that one of the reasons why informants agree to participate in a survey could be the hope that their experiences be of use for others.

<Data C>

M: Sorry, my talking is not so useful.

Interviewer: Don't worry. Your talk is very useful. I just brought a voice recorder today. I cannot concentrate on listening when I write down. I want to concentrate on your story.

M: I see.

To tell the inside story, I was taking notes mostly in the moments when the basic outline was being told. However I started listening without a pen right before this part. In that scene, Ms. M recognized her role, and it suggested that her strong wish to have her own experiences used for studies emerged.

-Change of the relationship between the interviewer and the interviewee by removing the framework

It is an interesting fact that more adorable comments came out of her mouth during a chatty talk after the formal interview. In the end, new surfaces appeared, and stories hidden at the formal scene have been seen once the framework of the interview was taken away.

5. The significance of narrative for an informant

At the end of the second interview, I asked Ms. M about the experience of expressing her own past and feelings, and she replied as follows.

<Data D>

M: At the patients' meeting, the major age group was beyond my mom's generation. They seemed to get used to the illness, in other words, they were well experienced, so that I don't think they can be my good fellow to talk.... Well, they did to some extent. They talked to me, but I long wanted to talk with some friends in the same age for a long time. So I'm glad that we could talk in this opportunity today.

This conversation confirmed that she had been waiting for a chance to talk with peers in her generation. In fact, people who attend patient meetings are mostly in their middle age and over while less teenagers and youths in the 20s come to them. That makes sense as to why the interviewee Ms. M asked me, the interviewer as an patient who have the same disease and an female in the same age group, questions. There are few places where patients are allowed to express themselves; therefore, active discussions on the importance of peer supports and self-help are necessary.

6. Multiple identity interaction

People live in society in which multiple roles exist within us simultaneously, though not

distinctively, and we are adjusting our face depending on relations with others and situations. As in this case, even if it was the place set up for an investigation interview, it was suggested that the conversation was generated not only as the relationship of an interviewer and an interviewee but also as the product of the interaction of the multiple roles. And the roles are what we all have, for example, patients (peers) or female fellows in the same age group. That led to the conclusion that conversations are the product of the interaction of the multiple roles which we all have, and there is no change in that when an interview takes place. And it isn't established that the interviewer who interrogates the interviewee has an authority. My story is just one of many examples. More diverse relationship could be created with a variety of different aspects, for instance, "a therapist and a client," "a senior patient and a junior patient," and "fellows who love music as a hobby. It is exactly interpersonal dialogue by persons pursuing their own topics respectively. Furthermore, the interviewer needs to give careful attention to that. So when arguing about narrative, it is important to focus not only on the contents but also on the place and relationship in which narratives are produced.

7. Reflexivity

In this case, the fact that we had the same illness was not the only reason why many different aspects of the relationship appeared one after another during the interview. Age and gender factors also greatly affected the dynamics of a relationship can occur in any situation.

"Reflexivity" must be considered as the most significant factor here. It is inferable that a researcher should be well conscious of the way in which the relationship with informants is built, how he/she should know their informants. Also a researcher should be attentive to his/her research purposes and emotion at interviews. Keeping enough room between self, informants, and the field, and avoiding unnecessary refusal of one's own involvement through the fear of criticisms or blame for lack of objectivity is important. Needless to say, I would like to devote a profound effort to the question of reflexivity relative to my doing further qualitative researches.

References

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