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(CARLS), Keio University**I. Introduction**

My report deals with the history and current state of patient association activities in Japan. First, I will define patient associations and research results of the self-help group (hereafter abbreviated as SHG). Then, I will survey the history and researches on patient association activities in Japan. Second, I will survey the ideal diabetic image of patient associations. Finally, I will share my new perspective with regard to research human relations of those illnesses.

II. Definition of Patient Association and Self-Help Group Researches

Patient associations in Japan are established by people with common illnesses and disabilities, families and healthcare professionals, and so on. These associations have various aims, such as improving public protection needs or social status, sharing and resolving the challenges in everyday life, exchanging information, and enlightening the society. In the Western context, the patient associations of Japan can be classified SHG. SHGs can be defined as small groups that are aimed at achieving reciprocal assistance,

and which are formed voluntarily and for a particular purpose. Typical origin of many currently existing SHGs lies in the Alcoholics Anonymous (hereafter abbreviated AA) in the U.S., many of which were formed in the 1930s. (Alan and Frank 1977, Katz 1993, Kubo and Ishikawa 1998)

The SHGs have been classified into groups. One of these classifications, provided by Katz, is 'the 12-step groups', and the other is 'non-12-step'. Those belonging to the '12-step groups' being to admit their helplessness through self introspection. This partly conflicts with modern humanity. A number of groups are aimed at helping people recover from addiction, which are represented by AA, and these are classified as '12-step groups'. In the '12-step groups', the problem tends to exist within the person. On the other hand, the 'non-12 step groups' involves many associations, including those of parents of children with chronic illness, divorced people, and women who had undergone mastectomies. Subscribing to one of these groups entails social stigma and, therefore, requires social support' (Miyachi 2003).

III. History of and Research on Patient Association Activities in Japan

The history of patient association activities in Japan is divided into three periods (Matoba 2001). The first period spans the 1940s to the 1950s. The council sanatorium was formed by people requiring long-term admission for recuperation from illnesses such as tuberculosis and leprosy. The second period covers the 1950s and the 1970s. Around this time, a number of patient associations were formed by people experiencing occupational illnesses, pollution-related illnesses, and drug-induced sufferings. The third period began after the 1980s. Around this period, people requested for the self-determination of cure prevention and rehabilitation. People in both these periods exhibit 'non-12 step groups' features.

I classify the researches of these Japanese patient associations into four orientations and researches. The first kind of those associations promoted by the people, concerns the people. They are oriented towards organizing social movements and recording their activities. The second is promoted by concerns people, welfare researchers and civil servants involved in welfare section. They are oriented towards filing the history of their activities and

achievements, researching on actual conditions, and introducing Western theories. The third kind is promoted by medical doctors and other co-medical staffs. They are oriented towards exploring the possibilities through which patient associations support the medical system. The fourth is promoted by cultural anthropologists and sociologists, and they are oriented towards analyzing the aspects of patient associations in the medical system and society. These in turn started roughly that along. However the research aspects of these orientations are added, not replaced. Without last aspects are employed at present.

The range of my research inclines towards the fourth perspective.

IV. Who is ‘The Ideal Diabetes Patient’? : Narrative from the Patient Association *Tsubominokai*

Who is ‘the ideal diabetes patient’? In this chapter, I find a solution to this question by examining the narratives of patient experience in the newsletters of the patient association for type 1 diabetes. These narratives are reactions against social bias and association members’ anxieties, and provide model stories. Therefore they are important data.

What is type 1 diabetes? This illness is a result of autoimmunity reaction and is mainly contracted by children. The incidence rate is 0.001%, and the prevalence rate is one per 10000 individuals. People with this illness need to undergo diet therapy, exercise therapy, and require administering 3-5 times self-injections daily. Thus, every treatment is a part of their daily life.

What kind of association is *Tsubominokai*? This association was established in 1964 and was the first patient association for type 1 diabetes in Japan. About 500 members belong to this association. *Tsubominokai* conducts courses twice a year and a summer camp for children, publishes newsletters, and promotes an enlightenment movement for the society, schools and members of this association.

Some members narrate their experiences during the courses for another members. These narratives are recorded in newsletters, which comprise the contents of this chapter. What do the members narrate?

They often narrate the changing attitude toward diabetes. The first attitude is influenced by coercion for example, ‘I have diabetes, so I (*don't*) have to

do something’.

- I had an illusion that ‘I can be the ‘normal’ if I worked harder than other healthy people’.
- I hated to talk about my illness and to be asked about it because I did not want to be considered peculiar.

The patient believed that their illness was a burden.

However gradually, they began to feel, ‘*I can do* something, because I have diabetes’.

- When I attended summer camp, I felt that I was not peculiar, and I understood my weakness.
- I am quite convinced, after I got diabetes.
- I am thankful that I had the opportunity to meet many attractive acquaintances.
- I accepted a challenge when I accepted my illness. I don’t compare myself with another person. If I did not have this illness, I would never have undertaken the challenge of the full marathon race.
- I received a job offer. This was the biggest turning point of my life. There is a company that offered me. Thereafter this, I started feeling absurd or negative. At one *nomikai* during the first year in the company, the personnel manager said ‘I asked you about your illness in detail and you replied very proudly. This confirmed that I absolutely wanted to employ you’.

Are these changes based on the improvement of the condition of diabetes? No. These changes are based on human relations. Some people provide the occasion of changes. The people are not only having same illness, but also have no point in common.

Therefore, according to the above mentioned examples, ‘the ideal diabetes patient’ sometimes fails but does not lose the illness and in turn uses the illness as a resource.

V. ‘Illness-related ties’/*byo-en* (“病縁”) in patient associations

We have already described the ideal diabetes patient. Finally, we need a viewpoint that is useful to study the state of the illness and human relations.

Therefore I propose the ‘illness-related ties’ concept. I have coined this concept, it implies that ‘ties between fellow human beings owing to their common illness form the pivot of their interrelations’, with tips from ‘kin’ (blood ties/ketsu-en).

The first characteristic of ‘illness-related ties’ includes ‘ties formed by common illness’. The perspective of a high school boy suffering from type1 diabetes was different. However, when he saw very young boys running around happily, he changed his attitude. He said, ‘I was in pain, but I saw my younger friends. They have so much vitality. I can also do the same!’ Further, he said that he had heard unthinkable tales regarding self-injection. He said that if his mother had the same opinion, he did not have to consent, because of the absence of illness. This is a very common pattern.

Another pattern of ‘illness-related ties’ is described as follows. ‘It can bond but not share illnesses and treatments’. Another boy does not inject in front of his classmates because of his fears of being bullied. However, once, he used the injection in front of his classmates. Contrary to his fears, his classmates watched him very compassionately. In addition, they considered him ‘courageous’ since he faced life despite such pain and suffering. This suggests that ‘illness-related ties’ can exist if there is two-directional communication that creates interest in the other party’.

Presently, the condition of human ties has transfigured. In the 1960s, Japanese anthropologist Yoneyama(1966) had pointed out that contemporary people depend on ties that are beyond blood ties and regional ties, that is, ties that are relation based ties (shaen). This tendency continues to the present day. Even the illness can be an opportunity of building ties. Therefore, we need to research this aspect further.

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Materials

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