Feasibility of "Medical Governance"
A case study of the Social Movement against the Limitation of the Social Health Insurance Fee Schedule for Rehabilitation Therapy in Japan

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[医療パーソナス]の可能性
日本におけるリハビリ療養費削減政策撤廃を巡る社会運動の事例研究

Abstract
People's movements that advocate patients' right to get appropriate healthcare services have emerged globally and deserve attention as important phenomena for improving healthcare systems. This case study focuses on the Japanese social movement that was created by patients and medical professionals who opposed the revision of the Social Health Insurance Fee Schedule of 2006. It illustrates the social process of the movement and examines the feasibility to create "medical governance", public participation and collaboration among various actors in health policy-making. Social Movement Theory and Professionals Theory were used as the theoretical framework of this study; the gap between them was bridged by examining the case. Data were collected from various sources, including interviews with activists, governmental documents, websites, newsletters, and media coverage. This study concludes that the movement can be recognized not only as a manifestation of the patients' rights and professionals' autonomy against institutionalized authority, but as a challenge to create a new platform for potential healthcare reforms.

和文要約
本稿は医療に関する社会運動という視点を採用しつつ、日本におけるリハビリ療養費削減政策撤廃をめぐる社会運動を事例に、人々の運動による保健医療の改革の可能性を論じるものである。医療に関する社会運動は、近年プライムタラによって論じられた概念で、医療社会学と社会運動学のギャップを埋め、市民の保健に関す運動による社会変革の可能性を示すものと捉えることができる。日本では全ての国民は公的医療保険に加入し、療養費削減によって効果的な医療ケアを受けることができ、2006年4月現行保険者、公的保険者によってカバーされるリハビリテーション医療の日数の上限を20188日と制限した。これに対して医療者や医療関係者から大きな反発の声が出たり、それは

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1. Introduction

All Japanese have public health insurance. For example, employees pay approximately 8 percent of their net income in premiums every month to the insurance organization associated with their place of employment. When they visit medical facilities, they pay 30 percent of the total fee for medical services as co-pay, and the rest of the fee is paid by insurance organizations from premiums and is subsidized by tax in certain cases. The Social Health Insurance Fee Schedule (SHIFS) lists the fees that the insurance organizations pay to the medical facilities for the insured’s medical costs. These fee schedules are organized according to the treatments, therapies, medications, and medical devices used, and are revised every two years in April by the Central Social Health Insurance Council (CSHIC), which is located in the Ministry of Health, Labor and Welfare (MHLW).

In early 2006, the CSHIC conducted a review of the fees for rehabilitation (rehab) services, and reported the recommendation to set limits on the number of insurance-covered days of rehab, depending on the original disease or injury – such as stroke, heart disease, trauma, and respiratory disease. Reflecting this report, on March 6, 2006, the MHLW informed all medical facilities that the maximum number of days of insurance-covered rehab would be 180 in total, starting April 1, 2006.

This announcement created a sensation among many people in different domains. Prior to 2006, the number of days of insurance-covered rehab was determined by physicians depending on the medical needs of patients. Patients in need complained that they would no longer receive sufficient rehab therapy. Medical professionals argued that necessary rehab would not be offered to a large number of patients under this policy and that the determination of the duration based on the original cause did not make sense in light of the principles of rehab medicine. Subsequently, individual patients, patients’ associations, and medical professionals formed a coalition, which was named the Association to Think about Social Health Insurance Fee Schedule for Rehabilitation (ATFR), to request the MHLW to withdraw the revision.

This action was remarkable in terms that people took an active role regarding a central component of the national healthcare policy, the SHIFS (Hosoda 2010a). By gathering signatures on petitions and constructing coalitions, people appealed to the Ministry to call off the new SHIFS regulation in order to provide them with the necessary rehab therapy. As a result of these efforts, on December 25, 2006, the MHLW released a new version of the SHIFS for rehab, which slightly modified the regulation by extending days of coverage for patients with specific conditions; this policy was implemented at the beginning of March, 2007.

Using Social Movement Theory and Professions Theory as frameworks, this study describes the social process of the movement to assert the rights of patients and professional autonomy in regard to healthcare, investigating the factors which have advanced or hindered the movement. I then examined the emergence of “medical governance”, which is a movement among various actors on healthcare, trying to create a new form for political conversation. Medical governance consists of public participation in health policy-making, in other words, collaborations of citizens, medical professionals and government workers to improve the quality of healthcare.

2. Theoretical Framework

Social Movement Theory and Professions Theory in Medical Sociology, developed independently, have generated much research implications. Social movements are defined as social processes wherein actors who are linked by informal networks and who share a distinct identity are engaged in collective action against clearly identified opponents (Della Porta and Diani 2005; Diani and Bison 2004). The opponents to a movement’s adherents and constituents are considered antagonists and could include state, national government, and corporate bodies (McAdam and Snow 2010a). When a feeling of dissatisfaction spreads, and insufficiently flexible institutions are unable to respond, social movements develop (Della Porta and Diani 2006:13).

Since the 1960s, social movement scholars have addressed four major questions: 1. What was the structural context in which the social movement developed? 2. How have the actors defined the social movement? 3. What were the available resources that made the social movement possible? 4. What is the interaction between the social movement and the political system? (McCarthy and Zald 1977, Sivula and Estes 2008). Answering these questions is the fundamental goal of this study, but to understand the case of ATFR, on which I focus in this study, the perspective on the actors should be modified by reconsidering the relationship between the supporters and the opponents.
While the traditional social movement scholars paid attention to the expansion of political-administrative intervention, called "new social movement" (Touraine 1981, Mellocci 1989), recent studies on health-related social movements showed that movements target not only governmental administration, but also other institutional authorities, such as medical professionals, hospitals, and research institutions (Levitsky and Banaszak-Holl 2010b). Indeed, we can cite a number of recent civil society activities around the world directed at medical professionals and healthcare authorities that have achieved progress in the treatment of certain diseases, greater social understanding of the diseases, and more guarantees for patients' rights. For example, a family at risk of Huntington's disease (HD), a heritable disorder, has established a foundation to seek genomic mapping of HD and to develop diagnostic techniques. Also, one of the family members has become a researcher involved in the genomics study of HD (Wexler 1995). AIDS activists have also received funding and attention from physicians to seek alternative or new treatments (Epstein 1998).

Another example is the Alzheimer's Disease movement, which has framed the disease not as an individual problem but a social issue (Beard 2004). Mental health and disability activists add further examples: their fight against social stigma and discrimination has been instrumental in achieving favorable public policies such as the Americans with Disabilities Act in 1990 (Brown 1984, Shapiro 1993). The above examples demonstrate how patients, victims, and their supporters have created informal networks in order to protest and change decisions made by medical professionals, researchers, and government; these are called Health Social Movements (HSMs) (Brown and Zavestoski 2004, 2005). The movement described in this study is HSMs, because it had attempted to change the professional's attitude to recognized as an example of healthcare policy.

In addition, according to my observations, the case is unique in that medical professionals played a significant role, along with patients, in changing the attitude of their own professional groups as well as the administrative interventions to improve people's rights to health 1.

Furthermore, a coalition of patients and professionals proposed an alternative policy and expressed their intention to participate in health policy-making process (Hosoda, 2010a). Therefore, the complicated and dynamic interaction and relationship among patients, medical professionals, policy-makers and government officers, which Crossley (2006) named "field of contention", should be counted as a part of traditional Social Movement Theory.

Given that medical professionals are important actors in movements to influence healthcare policy, I have reviewed some findings in the Professions Theory of Medical Sociology. According to the classical definition of Professions Theory, physicians are prototypical professionals in terms of their autonomy and altruism (Parsons 1950). Physicians as professionals working for the common good were distinguished from businessmen who sought their own interests. These notions, commonly accepted since the 1950s, were adopted critically into the concept of "professional dominance" as a negative characteristic in Medical Sociology by Freidson; physicians were viewed as the most powerful of powerful professionals (Freidson 1970).

However, scholars started to observe that physicians have lost their privileged position and power since the mid-1970s because of the rise of corporate and bureaucratic medicine, the emphasis on cost containment by third-party payers, and the empowerment of non-physician healthcare workers and patients as consumers (Starr 1982, Stoelcke 1988, McKinnel and Darceau 2000, Light 2000). Two sets of theories underlie these allegations, "deprofessionalization" (Laug 1973) and "proletarianization" (Larson 1979).

This theoretical framework accurately describes the global trend of the status of medical professionals as well as the present situation of the majority of Japanese physicians (Shindo 1999). Still, medical professionals are widely considered the dominant power that has a vast interest in protecting and reproducing existing authority structure (Levitsky and Banaszak-Holl 2010a).

My observation of ATFR and surrounding situation revealed that some, but not all, medical professionals cooperated with patients and contributed to the movement for the interests of patients. This professional's attitude may be partly recognized as ensuring quality within their profession (Levitsky and Banaszak-Holl 2010a). In addition, as Fox criticized Professions Theory to be "so nihilistic", failing to capture the reality of the physicians (Fox 1989a), certain characteristics of the occupational roles ought to be discussed in the context of altruism (Saks 1995). Moreover, the concept of "expert activit" which Frickel (2010:175) defines as professionals collaborating with a community-based protest, provides supportive perception for understanding the focused case. Based on these assumptions, the role of professionals who participated in the social movement was analyzed by employing classical definitions of profession, autonomy and altruism in this paper.

Brown (2005) noted that there is a gap between Medical Sociology and Social Movement Theory; many medical sociologists have studied such movements without referring to the social movement theory and literature, while social movement specialists rarely deal with issues of health. Also, some challenging studies have been performed by utilizing an integrated approach of social sciences, such as political science, sociology, and economics, and have contributed to better understanding of people's activities on health issues (E Great 2001, Heaney 2006). This multi-disciplinary perspective was applied to this study; both Medical Sociology and Social Movement Theory were used to depict the
complicated relationship between patients and medical professionals.

Additionally, this study goes further in exploring the feasibility of people’s – both patients’ and medical professionals’ – associations serving as agents for healthcare policy-making in examining how ATFR resisted political-administrative interventions in medical decision-making. ATFR insisted on the right of patients to get affordable healthcare, emphasizing physicians’ autonomy to determine the quality and amount of treatment to meet individual patients’ needs. This phenomenon can be interpreted as a suggestive alternative structure of healthcare policy-making.

In recent discussions of social science and public policy studies, “governance” has been a keyword used to overcome the distance between people’s needs and governmental control (Bevir and Rhodes 2003, Deacon 2005, Kuhlmann, Allsop and Sacs 2009). According to Maturo (2004), governance is defined as a method of coordination and orientation conducted by a large number of social organizations and networks, based on negotiation and participation, in a complex and risky environment. The concept of “governance” does not imply political dominance, but is conceptualized as an impelling force operating in a society outside government alone (Barry 2006). Using this perception, the current study elucidates ATFR as a representative governance in the medical domain.

3. Research questions and data collection

This paper will track and analyze the activities of the “Association to Think about Social Health Insurance Fee Schedule for Rehabilitation Therapy (ATFR)”, since the announcement of the new SHIFS in March 2006 till the appearance of the modified SHIFS in April 2007 (See Table 1). The following research questions are addressed: 1. Structural context of why and how ATFR emerged, and who the actors were, 2. the activities of ATFR, 3. the interaction and coalition of ATFR, 4. the consequences of ATFR activities, and 5. the definition of ATFR by the actors. By answering these questions, the factors that advanced and hindered the movement would be clarified.

Data were gathered from interviews and literature to investigate why and how ATFR activities took place, not just what, where, and when. Hence, this focused case study is presented descriptively to identify the reasons for the activities and their significance. As for interviews, I used “snowball sampling” to gather the interviewees out of the members of ATFR. The interviews were conducted from December 2007 through July 2010, and the participants include Dr. Tomio Tada, a stroke survivor and a symbol of the movement, Dr. A, a rehab doctor and a secretary of ATFR, Mrs. B and Mr. C from the Polio Association, Mrs. D from the Japan Traumatic Brain Injury Association, and Dr. E, a rehab doctor. I also communicated through e-mail with one government officer

<table>
<thead>
<tr>
<th>Year</th>
<th>Action</th>
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<tbody>
<tr>
<td>2006.03</td>
<td>The SHIFS new regulation up to 180 days was announced by MHLW</td>
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<tr>
<td>2006.04</td>
<td>The SHIFS new regulation up to 180 days was enacted</td>
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<tr>
<td>2006.04</td>
<td>Dr. Tada appealed his contesting new regulation in mass media</td>
</tr>
<tr>
<td>2006.04</td>
<td>ATFR was established</td>
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<tr>
<td>2006.05</td>
<td>ATFR started to gather the signatures</td>
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<tr>
<td>2006.06</td>
<td>JARM appealed government to revise the new regulation at the annual meeting</td>
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<td>2006.06</td>
<td>ATFR town meeting, the secretary of LDP sent a congratulatory telegram</td>
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<td>2006.06</td>
<td>ATFR submitted the 444,022 signatures to MHLW</td>
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<tr>
<td>2006.09</td>
<td>NAIPU conducted a nationwide survey to ask the effect of the new SHIFS regulation</td>
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<td>2006.10</td>
<td>The revision of the new regulation was discussed at the Diet</td>
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<td>2006.10</td>
<td>The JCP national Diet member appealed for ATFR at the Committee of the House of Councillors</td>
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<tr>
<td>2006.10</td>
<td>57 National Diet members attended “the meeting to oppose the new SHIFS regulation”</td>
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<td>2006.11</td>
<td>NAIPU final report indicated the estimation that 200,00 patients lost the access of rehab therapy</td>
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<td>2006.11</td>
<td>The chair of SDP questioned the director of MHLW at the National Diet</td>
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<td>2006.12</td>
<td>Representatives of local governments submitted statements to the MHLW</td>
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<tr>
<td>2006.12</td>
<td>MHLW announced the new regulation would be modified by April 1, 2007</td>
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<tr>
<td>2007.03</td>
<td>CSJHC submitted a modified SHIFS plan to MHLW</td>
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<tr>
<td>2007.04</td>
<td>The modified SHIFS was enacted</td>
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(Mr. F) in the department dealing with the Social Health Insurance Schedule in 2006-07. So the total number of the informants was seven. The interviews consisted of face-to-face sessions as well as personal e-mail communications before and after the meetings. Also, written materials were collected from various sources, including the websites of ATFR and other patients’ groups, newsletters of patients’ groups, governmental documents, and media coverage such as newspaper articles and editorials, TV programs, and weekly and monthly magazine articles.
4. SHIFS revision and the ATFR movement

4-1. Structural context of ATFR

When the announcement that rehab therapy would be restricted to 180 days evoked widespread negative reactions from those affected, the MHLW initially responded to these objections by indicating an alternative way; patients could use the services provided by the Social Insurance for Long-term Care (SILC). However, once the new regulation was implemented, patients realized they would no longer have access to rehab therapy and spoke out, arguing that “patients were cut off”, because the rehab provided by the SILC, which MHLW offered as an alternative, was limited in both quality and quantity compared to that provided under the original SHIFS. Dr. A, a professor of rehabilitation at a university in western Japan, immediately had a sense of protest against the new regulation, arguing that “even when great progress is not expected, it is important to keep up physical conditioning” and “there are many people with multiple diseases.”

(Interview with Dr. A)

Dr. Tomio Tada, a famous immunologist and a professor emeritus of the University of Tokyo, was one of the patients who opposed the new regulation. Dr. Tada was affected by a stroke in May, 2003, and had right-side paralysis and speech impairment. After one year of therapy, he had recovered sufficiently to be able to walk 50 meters with an iron cane. He was also practicing speech with therapists and used a personal computer to write essays on his stroke experiences and life history; ten of those were published, and one of them was awarded a prestigious literary prize in Japan.

Dr. Tada was asked by his doctor about the discontinuance of rehab in May, 2006, because the revision of the SHIFS would limit the insurance coverage to 180 days from April, 2006. Since he had already received rehab services for many years, he would no longer be eligible for the insurance (Interview with Dr. Tada). Although he managed to continue rehab, he thought the revision of the SHIFS posed serious problems.

“There are many people who cannot receive rehab even if they need it medically. Luckily, I still have it, but this is not a personal matter. The revision of the SHIFS does not respect the rights of the people with disabilities and lets us die. I will continue to protest against the Minister of Health, Labor and Welfare until they withdraw the revision.” (Interview with Dr. Tada, quoted by Asahi Newspaper, April 6, 2006)

Thus, Dr. Tada started to protest the revision of the SHIFS for rehab. At the same time, many people all over Japan, who needed more rehab, felt anxious about the revision and stood up to fight against it. Dr. A was convinced that the medical evidence did not support the MHLW’s decision and that the Ministry’s action deprived patients of their rights. He shared his views about the unfairness of the new regulation with his colleagues.

“Some patients recover after 180 days, if they receive more than 180 days of rehab. Although the evidence has not been established yet, I know a patient who recovered after seven months of rehab. Once I listened to the story of each patient carefully, many of them told me that they had recovered after many years of rehab.”

(Interview with Dr. A)

Dr. A used his blog to communicate with his colleagues, arguing for the retraction of the new regulation. He also used his personal network of patients’ associations and medical professionals to spread his ideas.

In April 2006, eighteen people, including patients, leaders of patients’ groups and healthcare specialists, established the “Association to Think about the Social Health Insurance Fee Schedule for Rehabilitation Therapy (ATFR)”. Most of the originators belonged to patients’ associations, such as the Center of Middle-aged People with Disability, Japan Traumatic Brain Injury Association, Youth with Head Trauma by Injury and Disabilities by Illnesses and Their Families Association, Higher Brain Dysfunction Association, Polio Association, and the Japan Stroke Friendship Association. Dr. A was one of the originators of ATFR, and Dr. Tada became the association’s leader. Dr. Tada’s objections to the new rule were accepted by many, including the mass media, which in turn greatly influenced public opinion on the matter.

4-2. Activities of ATFR

The remarkable activity of ATFR was a campaign to collect signatures on a petition to demand the retraction of the revision of the SHIFS for rehab. After a short preparation period, thirty staff members, who had never participated in this kind of activity before, stood on the streets of downtown Osaka to gather signatures, beginning on Sunday, May 14, 2006. The campaign to collect signatures was spread throughout Japan by various people. For example, an old man who learned about the campaign by chance made more than 1,000 photocopies of the form for signature, and handed them out to his friends, neighbors and others. A woman with spinal cord injury caused by an accident went outside using a wheelchair to gather signatures, which was the first time she had been outside since the accident.

In addition, ATFR created a website to publicize the unreasonable revision of SHIFS.
and to appeal for support for its retraction. Collection of signatures on the website was started on May 20. The number of signatures, examples of cases harmed by the revision, and reports of mass media were posted on the ATFR website day by day. After Dr. A appealed for signatures on his own website, three to four thousand people visited his site each week during the campaign. The power and attention generated by the huge number of signatures and comments from all over the country were considerable. Indeed, this effective internet usage in promoting the campaign would be termed "online social movement" according to Conrad (2010). In these ways, information technology changed the nature of the social movement by eliminating limitations caused by physical impairment and geographical distance (Fenton 2008).

The campaign lasted 42 days, from May 14 to June 24. During this time, 444,022 signatures were gathered (12,497 of them were submitted by Internet). That means that one out of every 290 Japanese signed a petition for the movement. Dr. A expressed the results stating that a "Chain of sympathy was created". ATFR submitted the signatures to the MHLW on June 20, 2006, accompanied by statement written by Dr. Tada. By the middle of July, 30,000 more signatures were sent to ATFR, and the total number of signatures reached over 470,000.

4.3. Interaction and collaboration

ATFR was unique to be organized by a variety of patients’ groups associated with conditions such as stroke, brain injury, polio, and spinal cord injury. These patients’ groups formed networks and collaborated beyond the specific needs of their types of disabilities and/or diseases; they publicized the ATFR movement through their newsletters and websites. Moreover, some of these patients’ groups were friendly with medical professionals whereas patients’ groups in general tend to be antagonistic towards medical professionals. In an interview, Mrs. B stated, "I think collaboration between patients and medical workers is important. We, patients, need to consider what to do to get their understanding and cooperation". As a consequence, the ATFR petition obtained widespread support.

Associations of healthcare providers had initially accepted the revision of the SHIFS for rehab. However, once they learned about the problems through the activities of ATFR, they changed their attitude and started to complain to the MHLW. For example, when the annual meeting of the Japanese Association of Rehabilitation Medicine (JARM) was held on June 2, 2006, members of JARM discussed the revision of the SHIFS for rehab. Dr. A was one of the JARM board directors and thought this change had occurred because of the pressure from public opinion and mass media which supported the ATFR (personal e-mail communication with Dr. A). Then, five rehabilitation-related associations—JARM, Japanese Association of Rehabilitation Hospital and Institute, Japanese Physical Therapy Association, Japanese Association of Occupational Therapists, and Japanese Association of Speech-Language-Hearing Therapists—released a report, making the MHLW reconsider the revision fundamentally.

The National Association of Insurance Physician Union (NAIPU) was also supportive for ATFR and conducted a nationwide survey from the end of September until the middle of November 2006, targeting its member physicians working at rehabilitation facilities providing intensive rehab for stroke patients. Answers from 362 facilities were received. The results indicated that at least 17,487 patients could not continue their rehab after the new regulation went into effect. In response to an open question, respondents replied: “even if patients had already received rehab for 180 days, they still have possibilities to recover”, “much rehab is needed for patients only to maintain their physical condition”, “if medical providers stop the rehab according to the SHIFS regulations, it means abandonment of the patients”.

Based on this survey, NAIPU reported that there were 200,000 (estimated) patients who had lost their opportunity to receive rehab therapy. This survey was mentioned on October 26, 2006, during the session of the Diet (Japan’s national parliament) where the limitation of days for rehab was discussed. By the end of 2006, medical professionals had similar ideas about the revision of the SHIFS as expressed in the survey results; “some patients do rehab by themselves, but it seems difficult to do alone”, “rehab using long-term care insurance is not good enough” and “rehab at medical facilities is needed for patients to maintain their physical conditioning”.

Viewed through the lens of Social Movement Theory, the favorable relationship between patients and medical professions created a unique activist identity that assembled strong power for the movement (Epstein 1996; Brown 2007). Interestingly, this was a new attitude on the part of patients, who more often took a negative stance toward physicians. At the same time, this was a new attitude on the medical professionals, who more often do not take a negative stance toward the government.

Besides, mass media could be counted as an important collaborator. Newspapers, magazines and TV networks published many articles and aired broadcasts about the revision of the SHIFS. Mass media outlets were critical for the policy of medical fee reduction which the MHLW had been conducting since 2002. The MHLW had reason to reduce medical fees based upon predictions of rising medical costs caused by a low birth rate and an aging population. Also, the long-lasting economic recession limits tax revenue to cover healthcare expenditure. Since the revision of the SHIFS for rehab was one of the strategies of this policy, mass media reported the difficulties patients faced under the revision and posed the question: "medical reform for whom?"
Moreover, mass media supported the ATFR campaign and contributed to the effort to collect signatures by reporting on the group's activities. When Dr. Tada handed all the collected signatures to the MHLW, many newspaper including three major ones (Yomiuri, Asahi, Mainichi) published a detailed article with a photograph. Mass media used the word "Rehab Refuge" so frequently that the word entered the dictionary as a new word in 2006. From March, 2006 until September, 2007 the ATFR's activities were mentioned in 140 national and local newspaper articles, 30 newspaper editorials, 14 monthly and weekly magazines and books, and 27 TV and Radio broadcasts. Again, returning to the theoretical frameworks, perhaps we can view the media as a previously unacknowledged but important partner in the social movement (Carroll and Hackett 2006, Kern and Nam 2009, Rodgers 2009).

4.4. Consequences

ATFR received supports from the members of the Diet belonging to both the party in government at the time (the Liberal Democrat Party: LDP) and the opposition parties at the time, such as the Communist Party of Japan (CJP) and the Japanese Communist Party (JCP). Many politicians attended the meetings and the symposia organized by ATFR. For example, the secretary of the LDP sent a congratulatory telegram to ATFR to express his support when a town meeting of ATFR was held in June, 2006. As another example, in October, 2006, Mr. Akira Koike, a member of the National Diet and a member of the CJP, advocated for ATFR and appealed for the retraction of the SHIFS's limitations on rehab at the Committee of the House of Councilors on Health, Labor and Welfare, showing the results of the NAIPIU survey. At that time, Mr. Hakuu Yanagisawa, the Minister of Health, Labor and Welfare answered that "the limitation should be flexible according to each patient's condition/situation".

When "the Meeting to oppose the new SHIFS regulation for rehab and to realize immediate improvement" was held at the House of Councilors on October 26, 2006, fifty-seven National Diet members attended. The LDP National Diet Members' League to examine the SHIFS for rehab and "National Diet Members' League to promote physical health and longer life expectancy" were created. Mr. Hidehisa Otani, a former Minister of MHLW, served as the chair of the latter league.

Mrs. Mizuho Fukushima, a chair of the SDP, questioned Mr. Kunio Mizuta, the director of the Health Insurance Bureau of the MHLW, at the National Diet on November 28, 2006. Mrs. Fukushima said that the specialist's opinion claiming that "ineffective rehab therapy has been done aimlessly for a long time", which formed the basis for the new SHIFS regulation, was not found in any formal documents. And, Mrs. Fukushima pressed Mr. Mizuta to answer whether the opinion was a fabrication by the MHLW. The following months, representatives of local governments, including Chiba City and Kobe City, submitted statements to the MHLW opposing the limitation of rehab therapy.

Although the MHLW received over 470,000 signatures on petitions collected by the ATFR and was under pressure from politicians, it did not respond to the ATFR at all, by neither e-mail nor phone call. However, on December 25, the MHLW suddenly announced that the new regulation of the SHIFS for rehab would be modified. Subsequently, the CSHC submitted a modified plan of the SHIFS for rehab to the MHLW on March 14, 2007, and the Ministry formally announced that a modified SHIFS (based on the CSHC plan) would go into effect April 1, 2007.

4-5. Definition of the movement

This movement was primarily defined as a movement to assert the patients' right to have affordable healthcare from patients' and medical professionals' points of view. Dr. Tada said "The revision of the SHIFS does not respect the rights of the people with disabilities". Another definition could be drawn from the viewpoint of medical professionals, insisting on professional autonomy. As Dr. E argued that "it is unreasonable to determine the days of rehab depending on the disease" (Interview with Dr. E), physicians demanded to determine the methods and amount of treatment and care depending upon the professional decision-making. Thus the movement can be recognized as a process helping physicians to obtain professional autonomy as well.

In addition, this movement indicated that medical professionals wanted to take responsibilities for patients despite opposition from the government. Dr. A believed that providing proper medical service is required for professionals (Interview with Dr. A). He argued for the retraction of the new SHIFS regulation on rehab coverage for all patients and became a secretary of the ATFR planning the campaign, including the collection of signatures. He thought of his activities as a "movement to support patients and ordinary people". When Dr. A had become a doctor, he had intended to stand by the most vulnerable people, such as those with disabilities and illnesses and the elderly. This attitude could be considered altruistic, even though it is not typical.

5. Discussion—Feasibility for Medical Governance

To summarize the social process of the movement, the ATFR was a health social movement, which was driven by broad coalitions to change the attitude of medical professionals and to express its objections to the institutionalized political-administrative intervention. Involving mass media, public opinion and politicians nation-wide, patients and medical professionals collaborated on an equal footing to assert patients' right to
health and professional autonomy, even though the movement did not fully attain its desired policy change. It is necessary to examine the factors working against the ATFR’s efforts. The power imbalance between the government and civil society and the lack of mutual understanding are pointed as the reasons why the efforts remained a partial success. This problem should be explored in the future research, but the movement suggested a hint to overcome this problem showing the intention to enact a part of “medical governance”.

Not only the movement focused on this study, but also several health-policy-related movements led by patients have been emerging recently in Japan. At first glance, it appears that people have complained about governmental regulation and health policy, but if we view the issue from a different angle, it seems that people wished to inform civil society and government that they are suffering from a lack of affordable healthcare and want to improve the situation. Medical professionals also want their stressful situation to be appreciated; even though they wish to provide adequate healthcare for patients based on professional decision-making, they cannot do so because of administrative restrictions. Thus, the recent movements seem to be seeking public participation in discussions on improving healthcare, creating a platform for “medical governance”.

Insight from political science provides some caveat. Esteves-Abe (2003) showed that citizens’ groups and government workers in Japan collaborated on social welfare policy in the 1980’s to create the new elderly care service system. However, these policy reforms were possible only because the movements were under the control of the government. These types of “state-society partnerships” might be described as examples of “governance”, but such cases could be more critically analyzed as “a state-sponsored grassroots movement” or “managed democracy” (Pharr 2003, Esteves-Abe 2003). Thus, it seems difficult for social movements to collaborate with government without losing their original motivation and autonomy. “Medical governance” is a contradictory challenge for social movements.

Although this case study covers a single movement and campaign, the findings would contribute to knowledge on Social Movement Theory and Professions Theory by viewing the collaboration between patients and medical professionals to change healthcare policy. We are facing challenges from growing healthcare needs because of a rapidly aging society and rising healthcare costs. In response, civil movements have emerged to combat inappropriate governmental healthcare reform. For example, in the UK, efforts to reform the National Health Insurance emphasize cost-efficiency over responsiveness to users (Taylor-Gooby and Wallace 2009). National Health Insurance reform has been criticized as risking throwing the baby out with the bathwater and echoes the situation prevailing in Japanese healthcare.

Footnotes

1 There are principally four sorts of Social Health Insurance in Japan: 1) Citizens Health Insurance, which is operated by municipalities for the self-employed and pensioners, 2) Government-Managed Health Insurance for employees of small to medium-sized corporations, 3) Society-Managed Health Insurance for employees of large companies, and 4) Mutual Aid Association for officials such as public office workers and public school teachers. The amount of the insurance premium and co-pay fees vary according to the insurance authority and individual income.

2 The details of the regulations of the rehab fees for each disease were recorded in the minutes of the eighty-third CSJIC meeting page 37, which is available on the website: http://www.mhlw.go.jp/shingi/2006/02/dl/s2003-3d3.pdf (Downloaded on April 14th, 2012)

3 There are some exceptions for example, people who have particular diseases, such as aphasia, and people affected by stroke who are predicted by physicians to improve.

4 According to the governmental statement on December 25, 2006, this announcement was released as “a reaction to people indicating their confusion”. The statement did not specify who the people were, but assuming “the people” to be those who had conducted the movement seems reasonable. http://www.mhlw.go.jp/topics/2006/03/dl/tp0314-la06.pdf (Downloaded on July 16, 2012)

5 A government officer, Mr. F, with whom I communicated by e-mail also confirmed that this announcement was a response to the ATFR.

6 To review the modern health and medical history of Japan from the perspective of health-related social movements, one should understand the specifics of the Japanese situation. There are several movements related to health matters, such as a movement from the 1950s by people with Hansen’s disease to improve living conditions and eliminate illness-related stigma, and a movement to seek causal factors and compensation for the health damage brought about by environmental pollution-related diseases like Minamata disease (Tosoda 2010b).

7 An appeal to seek rehabilitation therapy is not the same as demanding redundant rehab. It is reasonable to understand the assertion of disability studies that physical recovery is not the only solution (Oliver 1983). However, the ATFR movement
asserted there was a lack of rehab for people in need and did not come into conflict with disability studies.

6 The pile of petitions could fill two middle-size trucks.

7 This survey is available on the website
   http://hodenren.doc-net.or.jp/news/touhou/061204riha-bunn.pdf (Downloaded on April 14th, 2012)

8 This survey was printed in the newspaper Akahata, which is published by the JCP,
   on October 27, 2006.

9 The opinions quoted here were contributed to the ATFR homepage. http://www.
   careerseed.net/#anchor (Downloaded on April 14th, 2012)

10 Since 90 percent of Japanese households receive daily delivered newspapers, the
    reports carried in newspapers are considered to exert influence on public opinion.

11 The number of reported cases was tallied by the ATFR.

12 This information was cited by the Kyodo news, November 21, 2006.

13 When the Kyodo news asked the MHLW to disclose the document upon which
    "Professional opinion" was based, the MHLW responded that they heard the opinion
    of professionals face-to-face but did not have formal documentation.

14 All these politicians' activities increased pressure on the MHLW. According to the
    classical definition of professions theory, professionals are defined as persons who
    work for the common good, not for their own interest. In the recent election in
    August 2009, many candidates, especially those who were affiliated with the DPJ
    and the SDP, expressed their support for the movement and its goals. The DPJ and
    the SDP became a coalition government by beating the LDP, yet, as of April 2010,
    elected candidates have not changed the ruling. Are they working for the common good
    or not? If these politicians had worked for the ATFR and those who were suffering due
to a lack of rehab, but not simply for votes, we could call them professionals.

15 The modification which went into effect in April 2007 was more limited than the
    ATFR had demanded. The ATFR was working to withdraw the revision of the
    SHIFS which determined the maximum days of rehab depending on the causal
    diseases, but the modified plan just added several exceptions.

16 For example, the movement against prohibition of mixed usage of the SHIFS listed
    and non-listed drugs and the movement to terminate a newly established Social
    Health Insurance only for elderly over 75 years old could be considered such
    movements. The leaders of both movements have sued the government to solve the
    problems. Since these movements relate to my research topics, I will write about
    them in another paper.

17 Referring to the domain of environmental policy, some studies show that state
    agencies and social movements in Japan have formed coalitions and achieved
    favorable environmental policy reforms since the 1970s (Schreurs 2002, Brewster and
    Almeida 2004).

List of abbreviations

AIDS Acquired Immune Deficieny Syndrome
ALS Amyotrophic Lateral Sclerosis
ATFR Association to Think about SHIFS for Rehabilitation Therapy
CSHIC Central Social Health Insurance Council
DPJ Democrat Party of Japan
JARM Japanese Association of Rehabilitation Medicine
JCP Japanese Communist Party
HD Huntington's disease
HLW Health, Labour and Welfare
IISM(s) Health Social Movement(s)
LDP Liberal Democrat Party
MHLW Ministry of Health, Labour and Welfare
NAIPU National Association of Insurance Physicians Union
SDP Social Democrat Party
SHIFS Social Health Insurance Fee Schedule
SILC Social Insurance for Long-term Care

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