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Not Yet Cured: Taiwanese Hansen's Disease Patients Living with Sickness after Treatment

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Not Yet Cured:
Taiwanese Hansen’s Disease Patients Living with Sickness after Treatment

A dissertation submitted in partial satisfaction of the requirements for the degree Doctor of Philosophy in Sociology

by

Yi-ling Hung

2013
ABSTRACT OF THE DISSERTATION

Not Yet Cured:
Taiwanese Hansen’s Disease Patients Living with Sickness after Treatment

by

Yi-ling Hung
Doctor of Philosophy in Sociology
University of California, Los Angeles, 2013
Professor Stefan Timmermans, Chair

This dissertation offers an in-depth look into the paradoxical existence of patients who were cured but still sick. Modern treatment for Hansen’s Disease (HD) redefined the disease as a curable one and successfully eradicated it from Taiwan. Despite these, some patients remained sick. Issues regarding the existence of these patients were often complicated by the symbolic meanings of the disease as well as the protracted institutionalization of patients. In the last ten years, the renovation of the HD hospital in Taiwan has attracted the public’s attention, which in turn has raised the Taiwanese government’s awareness of the human rights issue of patients. However, the actual relationship between patients’ experiences and the medicine that treated them remain largely unstudied. The dissertation is based on historical data, interviews with patients and medical workers, and two years of ethnographic research in the HD hospital in
Taiwan that has accommodated HD patients since 1930. I examine the processes through which a synthetic compound became a cure for HD and facilitated medical understandings and practices that emphasized HD’s etiology. I also examine how patients continue to live with a stigma resulting from the interplay between the new medical understandings of HD and their body-biography trajectories already shaped by the disease. To live with bodies without sensations, patients have to constantly attend to the mechanics among the various objects involved when using their bodies for conducting daily activities. These efforts for managing stigma and disabilities were invisible in the current medical practices for HD, which were organized around mass treatment. The main argument is that the same change in medicine that led to a redefinition of disease and enhanced the overall efficacy of medical practices may also render individual patients’ experiences irrelevant. Life after being “cured” is still pretty difficult to the patients I studied. Only to these individuals, in whose life time an effective treatment for HD became available, did the disease become something that could have been cured and yet continued to shape one’s identity and daily lives. However, patients have come up with strategies to make sense of their sickness, cope with disabilities, and make serviceable a medicine that does not see what they have as an authentic disease—strategies sometimes including nothing else but to face and live with the sickness they still have.
The dissertation of Yi-ling Hung is approved.

John Heritage

Yunxiang Yan

Stefan Timmermans, Committee Chair

University of California, Los Angeles

2013
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<table>
<thead>
<tr>
<th>Abbreviation</th>
<th>Description</th>
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<tr>
<td>BI</td>
<td>Bacterial Index</td>
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<tr>
<td>CDC</td>
<td>Centers for Disease Control</td>
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<tr>
<td>DDS</td>
<td>Diamino-diphenyl Sulfone</td>
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<td>HD</td>
<td>Hansen’s Disease</td>
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<td>M. leprae</td>
<td>Mycobacterium leprae</td>
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<tr>
<td>SSS</td>
<td>Slit Skin Smear</td>
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<td>WHO</td>
<td>World Health Organization</td>
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Writing about disease, and, in a foreign language, was somewhat painful. However, I was very lucky to receive much help, which enabled me to take the pains as an unparalleled opportunity for transmutation.

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VITA

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INTRODUCTION

THE PARADOXICAL EXISTENCE OF PATIENTS

At about 9 am in the morning, Mrs. S walked into the treatment room to change her dressings. It was the busiest time during the day of the treatment room. Mrs. S brought what she wanted to use. It was powders packed carefully in a piece of paper. She asked the nurse to apply the powders to her wound. The powders were a chemical called Diamino-diphenyl Sulfone (DDS), a drug for treating Hansen’s Disease since 1952. Mrs. S obtained it from a doctor working in the HD hospital. It was meant to be taken orally. But Mrs. S made the pills into powders and packed them in sterile papers she had obtained from nurses. She believed that DDS would help her chronic wounds to heal. Based on her training, the nurse did not think that DDS had effects on the wound. But through her work in the hospital, she had learned to do what the patients asked as long as they did not seem to be harmful. That was an easier way for her to get her job done. But it was not always easy to foresee when things would go wrong. In the same morning, another patient who had just had an amputation came in to complain that nurses did not take care of her wound well. The nurses were unhappy to hear her complain because they had thought that the patients had insisted to go with their own ways (excerpts of field notes taken in July 2012).
THE PARADOXICAL EXISTENCE OF PATIENTS

In the hospital where Mrs. S lives, residents are sick with consequences of a disease that invades the nerves. In this dissertation I refer to the disease as “Hansen’s Disease” (henceforth HD) rather than as “leprosy” in order to emphasize the modern reinvention of the disease in the late 19th century.¹ Many of the people who were determined to have leprosy in the past would today be identified as having HD. Written records from India, China, and Greece contained descriptions that, according to physicians in HD writing in the late 20th century, were “surprisingly full and accurate, and testify to a high degree of observation and diagnostic skill” (Browne 1985:1).² This does not mean that HD and leprosy, or their defining criteria, were the same. Before the recognition of HD in modern Western medicine, generally corresponding diseases already figured as genuine medical entities in various cultures. These were called leprosy in Mediaeval Europe (Demaitre 2007), kushta in India (Sinha 2000) and li (癬) or lai (癬) in China (Leung 2009), and were explained with medical theories in the respective cultures. Not to underestimate the multiple correspondence and uncorrespondance between HD and leprosy (or kushta or li/lai), talking about HD is to emphasize that the realm I am studying is restricted to a disease whose history began in the late nineteenth century and whose defining criteria have been informed by modern clinical medicine and bacteriology.

One milestone in the history of HD was the expansion of the European awareness, first to the disease’s incidence in the West and East Indies. The definitive transition, however, came with the advances of clinical medicine and bacteriology. In Norway, Daniel Danielssen described the symptoms of leprosy with unprecedented precision in the 1840s, and his son-in-law G. Armauer Hansen identified the causative organism in 1873 (Demaitre 2007). Informed by these developments in clinical medicine and bacteriology, the first International Leprosy Congress
held in Berlin in 1897 recommended the strategy of segregating patients (Gussow and Tracy 1970).

The HD hospital where I conducted this dissertation research was built in this context. The Lo-sheng sanatorium was established in 1930 when HD was seen as highly infectious and a “national shame” in Japan, and thus a reason for people who had the disease to be segregated (Sato and Narita 2003). Built by the Japanese colonial government in a suburb of Taipei, the HD hospital was specifically intended for accommodating HD patients. In addition to compulsory segregation, there were also restrictions on certain aspects of the hospital residents’ social lives, such as marriage and raising children. Nonetheless, social life developed among the hospital residents in the form of exchange of labor, fraternization, and pastime activities such as gambling and chatting over tea. Religious life was also vibrant. A Presbyterian church, a Buddhist temple, and a Catholic church were built in 1952, 1954, and 1963, respectively (Chen 2006).

Compulsory institutionalization starting during the Japanese colonial period was later inherited by the Kuomintang regime after the Second World War.

In the first half of the 20th century in Taiwan, it was unfortunate to have HD, a disease that had no effective treatment and required segregation. Therefore when Diamino-diphenyl Sulfone (henceforth DDS) was adopted, it was almost like a salvation. In 1952, DDS was introduced to Taiwan to treat HD. Along with DDS, there was an official effort to redefine HD. An HD prevention committee was set up with the goal of eradicating HD. To bring out this goal, the committee adopted a mass treatment policy that emphasized treating a large amount of individuals with a standardized method. At the core of this policy was an understanding of HD as a specific disease with a cause, a standardized treatment, and prognosis. Under this policy, the HD hospital was redefined as a part of an out-reach HD prevention program.
Despite this official effort, a significant part of patients seemed to resist redefining HD. Out-patient clinics were set up at about the same time when DDS was adopted. In 1962 segregation policy was lifted officially. However, many patients volunteered to stay in the hospital. Some lived in the hospital until their deaths. Some left the hospital only to return to the patient community. Others volunteered to enter the hospital after the segregation policy was lifted. In 1962, 1035 patients remained in the HD hospital. The number decreased slowly, with a few patients being discharged or dying each year. In 1972, there were 919 patients in the hospital. In 1982, there were 781 (Losheng Sanatorium 1988). In 2010 when I was conducting this research, there were 235 of these patients, with an average age of 76.24.³

How is this situation possible: patients volunteered to live in a hospital for a highly stigmatizing disease when segregation was no longer required? This does not seem to be something random since the majority of the patients who were already hospitalized chose to stay in the hospital, and other patients volunteered to live there after being picked up by the out-reach program. The existence of this patient group is also paradoxical in another sense. Mrs. S who brought the DDS powders to the treatment room had peripheral neuropathy and thus could hurt herself easily. Also due to the peripheral neuropathy, the wounds might become chronic. The dead skin near the wounds had to be cut off each day. Occasionally, physicians came in to determine whether a minor surgery was necessary to remove the dead part. Medical workers, however, did not see much they could do beyond treating patients’ symptoms routinely.

Although the patients were officially classified as cases under monitoring, medical workers did not make efforts to detect indications of particular medical situations. On the other hand, patients insisted that medical workers do something to help. Therefore, at times medical workers had to improvise treatments, which were sometimes seen as outside of their professional realm. For
example, they prescribed DDS or applied it to patients’ wounds. Current medical workers and patients are both aware of the paradox. As a patient commented: “There are no longer patients like us. And no more doctors for this disease.” In the eyes of this patient, outpatients are different from patients like himself and his fellow patients. And the doctors treating HD today are different from their precedents. It is intriguing how patients and medical workers make sense of the prolonged institution of patients who were cured of the disease and yet were still sick.

Using the Taiwanese case, this dissertation addresses the question of how the actual effects of a treatment are locally worked out by medical workers and patients. As such, the dissertation emphasizes the role of medicine, rather than the role of factors surrounding it. Existing studies on this HD population in Taiwan or HD populations in other countries have also observed that some HD patients continued to live in an institutional environment even after HD became curable. They have emphasized the role of segregation policy that forced patients to be institutionalized or made patients dependent on hospital lives (Chen 2006; Fann 2009; Gussow and Tracy 1970; Sato and Narita 2003). Despite shedding light on the social factors that led to a stigmatizing segregation policy, these studies are less helpful for understanding the relationship between patients’ experiences and the medicine that treated them. Rather than focusing on how a segregation policy forced patients and how patients either conformed to or resisted the policy, I explore how patients’ experiences were shaped by the redefinition of disease underlying the adoption of an otherwise effective treatment. I will show how patients found ways to coexist with their illness and to make modern HD medicine serviceable for them.

FROM CONTESTATION TO COORDINATION
HD has carried a stigma in various cultures that it inherited from its precedents in history. From the beginning, it was a frightening disease that led to deformities and disabilities and was not curable. When sulfone treatments were claimed to be effective in the late 1940s, it was quickly adopted in the US, and later in many other countries. The effective medication redefined HD as a treatable disease and the involvement of nerves as a preventable condition. Previously a disease that could be passed from one person to another and that sooner or later invaded the nerves, HD became a disease whose cause was specific and preventable. Policies based on this new understanding proved efficacious in eradicating HD on the population level in many countries. To physicians, this was a successful story of science-based medicine. In the terms of science studies, there has been a consensus, or closure, in medical communities (Latour 1987) in the mid-20th century about the efficacy of medications for HD.

In comparison with many other diseases, the story of HD medicine since the early 20th century has lacked contestation. Users of HD medicine, doctors and patients included, have not made explicit efforts to reshape the etiology and treatment of HD. Medical sociologists have studied diseases or medical situations that were under contestation. Focusing on medical practices—what medical workers actually do to treat patients—this literature emphasizes the content of medicine as an important aspect of social relations taking place in medicine (Casper and Berg 1995). Along this line, a rich literature has focused on how various actors make claims and negotiate with each other to come up with an order for doing medical work (Casper 1998; Clarke and Montini 1993) or to gain credibilities in knowledge communities (Epstein 1996). In this literature, when patients are studied, the focus is often on patients who make explicit efforts to resist or challenge the reducing effects of medicine. It is amazing how patients are able to obtain the language of medical practitioners in order to influence medical understandings.
Patients become lay experts and are sometimes able to gain credibilities in the medical communities.

However, there has not been enough attention on situations in which patients become knowledgeable of their own disease not in order to participate in contestations over the disease, but to find ways to live with it. A few exceptions are recent studies on patients of atherosclerosis (Mol 2002), diabetes patients (Mol and Law 2004), and individuals addicted to heroin (Gomart 2002b). In these cases, medicine receivers make members of medical communities respond to their needs without reopening the contestation all over again. Instead, they find ways to make existing medicine serve their needs. The lack of attention on such actions of patients is not surprising since it is difficult to follow patients through the ups and downs of their illness to understand what they actually do to manage the unpredictable bodies. The scenes medical needs come up are more scattered and random than knowledge production or medical work. The unpredictable nature of bodies with illnesses (Strauss and Glaser 1975) makes the advice of following what actually need to be done (Latour 1987) difficult to follow.

This lack of attention on situations in which patients find ways to make existing medicine serviceable constitutes a discrepancy between literature and actual medical scenes. In some situations, patients lack the resources or the cultural background to turn themselves into competent members of the medical communities (Abraham 1993; Fadiman 1997). Moreover, it is part of actual practices of medicine that patients and doctors tinker together to find a way to accommodate medical interventions with the many ongoing events of everyday life (Mol and Law 2004). Finally, the insistence that medicine provide an ultimate solution to suffering might sometimes be a myth. After all, there are situations in which medicine has not fulfilled, and might not fulfill, its promise. Even after the advent of cardiopulmonary resuscitation as a
treatment for sudden death, there is no possibility to change the fact that human beings inevitably
die (Timmermans 1999). And there are sufferings that just cannot be explained in the terms of
objective evidences and the best physicians can do is to give “functional diagnoses” (Aronowitz
1998). Rituals (Timmermans 1999) and flexibilities (Mol and Law 1994) are often part of what
keeps medicine as a social activity going. Therefore, there is a need to pay attention to situations
in which patients, in ways other than reopening the closure all over again, find ways to have their
sufferings come to terms with conventional medical understandings.

My study on treatment for HD and HD patients is a step in filling the gap in existing
medical sociology. The lack of getting in contestation did not prevent HD from constituting a
strategic field for studying the content of medicine. In the case of HD, there is a misfit between
what constitutes symptoms and what constitutes a genuine medical entity that justified medical
interventions. The HD patients I studied coped with this misfit not through getting involved in
contestations. Instead, they join in tinkering with medical workers of various generations. These
patients provide a window through which to understand situations in which a misfit between
formal understandings of disease and illness experiences is an integral part of the content of
medicine and is built into medical institutions. Studying how these patients find ways to make
medicine serviceable for them helps to understand how patients become knowledgeable not to
contest, but to coordinate—to do something so that the various people involved work together to
achieve a better result.

Patient groups who experience a misfit between formal medical understandings and
illness experiences are not unique in modern medicine. An example is “remission society.”
Members of remission society live temporarily without symptoms (of, for example, cancers) but
are subject to periodical check-ups. They are individuals who are effectively well but could not
be considered cured. They could have been dead because of their serious illnesses, but have returned to their previous obligations because of the scien-technological achievements of medicine. However, living in the wake of illness, they find their obligations to be never again what used to be normal. They also find medicine still existing in their lives in the form of periodic check-ups or memories. Living with illness for the long term and refusing having the particularity of their individual sufferings reduced to medicine’s general view, members of remission society claim their own individualities through measures outside of conventional medicine. For example, in self-help groups, members of remission society hold onto their own stories as one specific activity of constructing the self and an exercise of responsibility (Frank 1995).

Like members of remission societies, the individuals I studied live continuously with a misfit between formal medical understandings and illness experiences. However, the misfit they have lived with marks a change in medicine for efficacy, rather than an inadequacy in medicine. Using Aronowitz’s terms, I call the individuals I studied “orphaned patients”—patients who are sick with what used to be part of a disease. Using examples of heart disease, Lyme disease, and chronic fatigue, physician and medical historian Aronowitz (1998) illustrated a phenomenon that he called “orphaned knowledge” (ibid.: 173). Orphaned knowledge results from reclassification of diseases and involves changes in the social meaning of disease—how to understand the cause of disease and the efficacy of treatment as well as how to decide who is responsible for the disease. In the example of heart disease, when the meaning of angina pectoris changed from a characteristic patient experience to the clinical correlate of a specific anatomic abnormality, not only did certain patients lose their diagnosis, but also much knowledge and clinical experience were made irrelevant. For instance, how to make “personal diagnoses” of the typical angina
patient or how to use a rich set of hunches about the relationship of specific behaviors to later disease became not useful. In a similar manner, as HD became a curable disease and the medicine that existed when they first became sick became orphaned knowledge, the HD patients I studied found themselves living with lingering symptoms that used to be seen as part of the disease but they had lost their diagnoses. Living with symptoms that do not match a diagnosis, patients live with the illness as their own responsibility. The negotiation over what constitutes symptoms and what constitutes a specific disease is a daily reality of patients’ lives. A lot of interpretations by the patients is required to make sense of the official status they were assigned and to find resources they can use.

The analysis of the consequences of HD reclassification provides a rationale for the paradox of HD. The prolonged institutionalization might appear to be a sign of lack of agency on the patients’ part. On a deeper level, the paradoxical existence of the patient group is witness to patients’ efforts to live with a misfit that defined their existence. The lack of contestation of the HD story is therefore actually what makes it interesting. The study on HD promises to illustrate the situations of an institutionalized misfit between formal medical understandings and illness experiences, and to provide a scenario of active patients alternative to those portrayed in existing literature. In the case of fibromyalgia story, patient-consumers empower each other to find their symptoms framed in conventional medical terms (Barker 2008). Through electrical self-help communities, patients of fibromyalgia empower each other to believe that their sufferings are authentic and to turn to doctors who would give the diagnosis. HD patients also try to come to terms with conventional medical framework. They do so not by acting as patient-consumers. Instead, they form a “disease constituency”—they constitute a category that is not officially recognized, but is nonetheless an integral part of the institution. Pushing and pulling life into
various forms, patients make themselves included in actual medical work. The HD patienthood, a kind of biological citizenship (Petryna 2002) in a literal sense, is a product of interactions between medical knowledge and medical practice.

**MAIN CONCEPT: ORPHANED PATIENTS**

Even with the general thread on the modern redefinition of HD, this dissertation does not engage with the debate of whether or not diseases are constructed. Rather, it focuses on the specific ways in which various actors are influenced by and respond to the redefinition of a disease. For example, how patients find ways to make serviceable a medicine that does not fit their experiences. Asking how certain individuals become recipients of medical service means that I do not see consequences of a disease as determined by the physiological features of the disease. Rather, consequences are locally worked out by medical workers and patients.

The core concept of the dissertation is “orphaned patients.” This concept builds on existing discussions of patients’ role in medical sociology. Parsons sees patients as constituting an integral part to successfully bringing out medical work. He defined patients as the recipient of the services of a scientifically trained professional physician (Parsons 1979 [1951]). Refining this conceptualization of patient, studies on chronic illness patients show that patients are active in the senses that they do a part of work that is usually seen as professionals’ job (Strauss et al. 1982) and that they do a lot to cope with disruptions to their biographical trajectories (Bury 1982; Carricaburu and Pierret 1995; Charmaz 1991; Williams 1984). Patients are also active by becoming knowledgeable of the content of medical science applied to them, sometimes playing the role of lay experts (Epstein 1996). Inspired by science and technology studies, recent literature has illustrated how patients integrate technological objects in everyday lives. Patients
enact their disease in various forms: they handle the incompatibilities between the different departments of the same hospital (Mol 2002), objectify some of their sex organs in order to become pregnant (Thompson 2005), allow themselves to be addicted temporarily to a substance in order to break free from heroin (Gomart 2002), and bear the anxiety resulting from diagnostic uncertainties (Timmermans and Buchbinder 2012). These efforts are an integral part of what make a clinical unit (Mol 2002), a technology (Thompson 2005), a drug (Gomart 2002), or screenings (Timmermans and Buchbinder 2012) work. These research avoid being functionalist and yet point out ways in which patients constitute parts of medicine.

Drawing on discussions of patients in traditions of interactionism and science and technology studies, I come up with my own conceptualization of patients as recipients of medical service. There are three filaments of the idea of orphaned patients. First, the context in which orphaned patients find themselves is characterized by a misfit between formal medical understandings and illness experiences. Second, orphaned patients act constantly and adaptively for the enactment of disease—they pull and push lives into different forms to live with their disease as a daily reality. Third, patients’ experiences are also shaped by the bureaucracy of medical work.

I. A Misfit between Formal Medical Understandings and Illness Experiences

Focusing on the paradoxical existence of patients who are cured but continue to be sick, the concept of orphaned patients focuses on a situation in which there is a misfit between formal medical understandings and illness experiences. This concept asks whether and how this misfit can be institutionalized into a medicine that has otherwise been effective. The concept of
orphaned patients traces the physical and social consequences patients live with to their roots in medicine’s pursuit of efficacy.

In his seminal work, Parsons sees modern medical practice as organized about the application of scientific knowledge to the control of disease. In his conceptualization, in a medicine structured as such, the situation of the sick person is characterized by the combination of helplessness, lack of technical competence, emotional disturbance, and difficulties in making a high level of rationality of judgment (Parsons 1979 [1951]). The concept of orphaned patients follows this conceptualization of modern medical practice as organized about the application of scientific knowledge to the control of disease. However, it emphasizes that this way of organizing medical practice is a result of particular historical processes, such as developments of disease framework (Aronowitz 1998) and medical disciplines (Rosenberg 2007). Paying attention to the particular historical processes that shape the organization of medicine, the concept of orphaned patients explores medical practices that are rational in one realm of medicine (such as pathology), but not in another (such as clinical medicine). As such, the concept complicates what is framed as lack of technical competence or high level of rationality in Parsons’s work.

II. Enactment of Disease

The idea of orphaned patients is about how a disease is enacted. Orphaned patients live continually with physical consequences of disease. Since there is a misfit between formal medical understandings and illness experiences, how do relevant individuals decide who is responsible? What are the consequences for medical professionals’ work and for patients’ biography? How do patients cope with the consequences?
The misfit between formal medical understandings and illness experiences means that there may be an ambiguity in the roles of relevant individuals. There may be efforts that are not officially admitted (Strauss et al. 1982). There might also be incongruence between what patients and medical professionals think what they should do, and what they actually do. The idea of orphaned patients asks whether and when such incongruences exist.

Since the idea of orphaned patients touches upon the incongruence between what patients need and what they are actually provided, a relevant question is what patients do to bridge it. As existing literature points out, in the real scenes of medical work, it is pain in the leg (Mol 2002), the wish to become pregnant (Thompson 2005), the desire for freedom (Gomart 2002), or the anxiety over the continual existence of a newborn (Timmermans 2010) that drives the actual practices. Adding to this anthology, the concept of orphaned patients explores what it is that drives patients to live with a medicine that cures them but does not save them from illness.

III. Bureaucracy of Medical Work

The idea of orphaned patients also emphasizes the bureaucracy of medical work. Like other institutions (Stinchcombe 1959; 1986), medical institutions adopt certain ways of organizing the content and routines of work in order to be efficient in the context they operate. What is considered efficient is determined contextually. Some of the work professionals do might be very symbolic, but may constitute an inevitable part of what makes medicine work (Parsons 1979 [1951]) or how medical workers become able to execute the job of taking care of the strangers (Rosenberg 1995). In the US in the late 19th century, bureaucracy was seen as an efficient way to organize hospitals (Rosenberg 1995). But the inadequacy of the same way of organizing became salient in the late 20th century (Rosenberg 2007).
Orphaned patients constitute a challenge to conventional ways of organizing medical institutions. On the one hand, the administration of medical work proved to be effective on the population level. On the other, medical workers may feel challenged because of having to deal with patients who live with social and physical consequences rooted in medicine and not being able to provide the help in the ways they are supposed to do. It is intriguing how medical workers socialize into the role of doing the job but not really helping in the way both patients and they suppose themselves should do.

**LAYOUT OF THE DISSERTATION**

Using this framework to synthesize the various aspects of HD redefinition, I construct a narrative of how medical knowledge and practice interact to produce and respond to a redefinition of a disease. For doctors, HD becomes an easy disease to treat. But for patients, they have lost their credibility for making complaints based on the symptoms they have. They have to find ways to live with their sickness in coordination with existing medicine. Doing so, patients simultaneously, and paradoxically, expand and challenge the credibility of medicine. In each of the chapters, I focus on one of the most interesting aspects of the redefinition of HD starting in the early 20th century. Each of the chapters has its own theoretical package and illuminates certain aspects of the process of HD redefinition. Chapter One and Chapter Four constitute the backbone of this dissertation. They analyze the epistemic communities HD is embedded: the shared beliefs, routine practices, ways to evaluate efficacy, and sources of credibility. In Chapter Two and Chapter Three, I analyze how the new definition of HD was translated into the lived experiences of patients.
Chapter One follows the gradual constitution of DDS as a cure for HD. I examine the experiments that tested DDS for its curing effect. I show that DDS as a chemical is not enough to cure. It was physicians’ bricolage—manipulating the dose of DDS, and taking risks in trying a potentially toxic material on patients in pursuit of the possibility of curing a then incurable disease—that found a way to release the curing effect of DDS. Therefore, DDS emerged from physicians’ expertise. However, when it became a cure, the efficacy was attributed to the substance itself. With DDS as an important component, the new HD classification defined HD based on its etiology more than on its symptoms.

In Chapter Two, I analyze the body-biography trajectories of HD patients to explain expectations and fears of stigma patients still live with even after they were cured of the disease. Using interview data, I will show that the expectations and fears of stigma were a result of the interplay between the new medical understandings of HD and patients’ body-biography trajectories. The introduction of DDS as a cure differentiated between the “real disease” and the visible signs of the disease. Under this view, patients who were cured of the pathogens but still had lingering symptoms did not have the disease. However, to the patients, the disease was still real as a part of their body-biography trajectories. Having deformities and disabilities, patients found it difficult to establish a new identity on the outside. In the end, many stayed in the hospital. Still carrying visible signs and failing to resume social roles on the outside, patients thus expected and feared stigma—not stigma associated with the “real disease,” but stigma associated with their discredited aspects of identity.

Chapter Three focuses on the body experiences of patients. From patients’ perspective, instead of being cured, they were transformed by the medicine that became able to treat HD effectively. Instead of simply bearing the physical effects of a disease, patients live protracted in
an ontological gap created by the medicine that aimed to cure them. Living protracted in the ontological gap requires much effort to deal with challenges that are at once practical and normal. This chapter focuses on how patients practice the “body mechanical,” a set of skills patients developed to keep their bodies functional. The body mechanical requires patients to attend to the mechanics involved when using their bodies for conducting daily activities as well as to practice a form of self-awareness. I argue that patients demonstrate a way of being active through embracing and coping with the state of being sick.

In Chapter Four, I will show how the same set of medical practices that aimed to deliver the cure to patients made patients’ experiences irrelevant. I do so by following a rationalizing tool of the HD prevention program—the slit skin smear (SSS) examination. The work of the HD prevention program became more bureaucratized after adopting the SSS examination. This reorganization did improve the overall effectiveness of the medical work. However, it also defined infection as the authentic disease that required intervention. As such, the experiences of patients who were cured but still sick were left out. The continual execution of SSS examinations filled in the rupture in the rationalizing tool and the aim of medical work by providing a convenient justification of the prolonged institution of cured patients. At the same time, it further makes experiences of a part of patients irrelevant.

In Conclusion, I return to the concept of orphaned patients. I provide a first step of theorization of this concept in light of the patient experiences and medical practices I studied. I argue that the concept is helpful for studying situations in which medicine, instead of saving people from consequences of a disease, transforms the consequences. Finally, I revisit the paradoxical existence of patients and conclude by suggesting that acknowledging the normality of pathological bodies can be a constructive way of arranging social life.
FIELD SITE AND METHODS

After a renovation in the early 2000s, the HD hospital was composed of two tall buildings with modern hospital facilities: a 193-bed acute medical facility for general citizens and a 300-bed nursing facility in place of the Lo-sheng leprosarium built during the Japanese colonial period. Expecting that the majority of its patients would die in the near future and the building would be converted for some other use, the administration began to use its street-side building as a community hospital. The doctors and nurses began to divide their time between general citizens living nearby and HD patients. The HD patients lived on the second to ninth floors of the rear building. On the southern part of the first floor was a hallway leading to the front building, a hall, a retail store, and an administrative office. The northern portion housed the pharmacy and clinics. There was also a consulting room for the rehabilitation division, a room for physical therapy, a room for changing wound dressings, and a room for internal medicine and surgeons. A timetable was hung on the wall outside of the pharmacy so that patients could conveniently make appointments. In the hallway outside the consulting room there was a row of chairs. While sitting on the chairs or on their own scooters and waiting for their appointments, the patients would chat with each other, exchanging news about other patients.

I conducted my fieldwork between October 2009 and September 2011. I also returned to the field for a month in July 2012 to collect data for questions occurring to me when I was doing data analysis. I started the fieldwork as a volunteer. As a conventional role of the hospital, a volunteer gave me easy entry to the field. This, though, confused some patients, because I was present more frequently than other volunteers and was writing notes and asking questions, rather than just doing jobs volunteers were supposed to do. Later I decided to make it explicit that I was
doing research and found the explicit identity as a researcher less constraining for my interactions with patients.

The fieldwork took place in the rear building of the HD hospital as well as in the sanatorium that had existed since the colonial period. The waiting area outside of the clinics was an important meeting point. Most of the patients needed some sort of medical service on a daily basis and visited the clinics as a daily routine. I found initial participants by approaching patients when they were waiting for their doctors. I spent time sitting with the patients as they waited. From there I followed them to their homes and then to their shopping trips and friend visits. The patients approached were neither randomly selected nor representative. Few of them declined to participate in the research. I joined gatherings such as the tea tables, church gatherings, and funerals. These visits resulted in several different snowball samples. Three key participants proved to be instrumental in providing introductions to different networks. I befriended “Mrs. Z” and some of her friends, particularly “Mrs. Y” and “Mr. K.” These participants—regarded as my main informants—were also instrumental in providing access to social events where other patients gathered. For most of the others, I remained an acquaintance and knew them by name. I also spent time watching medical work. I jotted down notes while observing and wrote my field notes either on the same day or the day after. Every visit to the field site resulted in several pages of field notes; the two years of research have resulted in hundreds of pages of field notes.

I observed patients in different ages. Most of the patients were in their late seventies. The youngest were in their early sixties. There were more men than women, with a rough ratio of 2:1. Not many patients had children. Even those who did tended to assume that they would live without children nearby, since the hospital allowed only patients and individuals who did the nursing jobs for them. However, some managed to buy a house or apartment next to the hospital.
and had children living there. These patients themselves either spent time on both locations or had the children visiting frequently. Patients with higher nursing needs lived in the units on the second and third floors, where nurses were on call for 24 hours. Units on these two floors had multiples beds in each of them. The layout of units on the fifth to ninth floors was similar to regular apartments. Each of the unit had one restroom. However, there were only two kitchens on each of the floors. Patients could choose to have the meals prepared by the central kitchen of the hospital. But most patients preferred to cook for themselves or to have someone cook for them, so that the meals were tailored to their individual preferences. In response to this need, there was a vendor cart run by a patient, opening on every Tuesday, Thursday, and Saturday, offering fresh food materials.

Over the two years, I saw patients moving from the upper floors to the second or third floor. Observing fellow patients becoming weaker, patients were aware of this gradual decline of bodies and learning to normalize the experiences. Some of their body experiences were more common ones to people at their age. Others were peculiar to them as HD patients. The body experiences developed into the main theme of Chapter Three.

I interviewed 35 patients. I asked open-ended questions about the influences HD brought to their biography and their illness experiences. Formal interviews took place at patients’ homes and public spaces in the hospital, and were audio recorded and lasted between half an hour to two hours. I conducted informal interviews while walking with patients. I did not audio record informal interviews, but generally covered the same themes. I used direct quotes from the formal interviews and paraphrased informal interviews and conversations. I also conducted three formal, audio-recorded interviews with family members. Finally, I interviewed seven medical workers
(including two doctors, two nurses, one medical technician, one physical therapist, and one laboratory researcher).

All of the interviews were conducted in Mandarin or Taiwanese by the author. The author or a hired transcriber transcribed the formal interviews verbatim. Informal interviews were reconstructed from memory and notes taken on site. When possible, data collected through informal interviews were presented to the interviewee for confirmation and correction of sentiments expressed and documented. In no case were data modified after this verification process took place.

The internal documents collected from the hospital included statistics, work reports, and regulations regarding HD in Taiwan. A library in the hospital had a collection of the internal documents. I was allowed to borrow and make copies of them. I also gathered medical publications focusing on chemotherapy for HD and rehabilitation for post-treatment patients. I used the archive of the *Journal of the Formosan Medical Association*, which covered journal articles published in the colonial period and those published after World War II. From the writings of the doctors working in Taiwan I traced to other researches that focused on the treatments of HD.

The writing of the field notes followed Emerson and his colleagues’ (Emerson et al. 1995) guideline for writing ethnographic field notes and focused on concrete details for describing the ambience of a setting or environment that is important for understanding subsequent action. I started data analysis and accumulation of memos right after entering the field. Field notes and interviews were coded into themes for analysis. Coding, organizing, and analyzing of data were based on grounded theory methods (Corbin and Strauss 2008). I
developed concepts by comparing different situations of the interactions I registered. I also refined the concepts by going back and forth between concepts and data.

Endnotes

1. When names of specific organizations or projects are mentioned and the name uses “leprosy” rather than HD, I will still use “leprosy.”

2. There were also studies in the tradition of osteoarchaeology. These studies examine skeletons and other remains for signs that correspond to modern definitions of HD. But this is a different issue from exploring the correspondence or uncorrespondence between leprosy and HD.


4. There has been a rich body of literature on this topic, particularly about mental illnesses. See, for example, Chesler 1972; Ehrenreich and English 1973; Horwitz 2002; Kitsuse 1962; Laing 1967; Oakley 1981; Scheff 1984; Smart 1976; Szasz 1974.
CHAPTER ONE

THE GRADUAL CONSTITUTION OF DDS AS A CURE FOR HANSEN’S DISEASE

DDS started to be used for treating HD since the late 1940s and has remained a first-line drug for HD today. It was one of the earliest antibacterial drugs that were known to be effective. Despite the problem of DDS-resistance developing in some strains of bacteria, DDS was evaluated by many medical workers to be a major accomplishment of modern medicine (Spink 1978). In modern text books for HD, the treatment of HD is divided into the pre-sulfone era and chemotherapy (Hastings 1985).

In this chapter, I follow the gradual constitution of DDS as a cure for HD. I do so by focusing on two experiments: a 1937 experiment conducted at the Physiological Research Laboratories of the Wellcome Institute, and a 1948 experiment conducted at the Leprosy Research Unit in Nigeria. The former is one of the earliest experiments in which DDS was tested for its bactericidal effects. The latter is one of the earliest experiments in which DDS was tested as a cure for HD. The 1937 experiment adopted a rigorous, scientific approach in the field of chemotherapy. According to this scientific approach, DDS was toxic and not suited for using as a drug. It was not until 1948 that DDS was rediscovered. In the 1948 experiment, a physician took risks in applying DDS to HD patients. He was skillful in manipulating doses to find a level at which DDS would be bactericidal but not too toxic to human bodies. It was in this 1948 experiment that DDS emerged as a drug. Analyzing the processes through which the two experiments came to their respective conclusions, I argue that it was physicians’ expertise and bricolage that specified a condition for DDS to work and, as such, released the power DDS might
have had as a drug.

THEORETICAL FRAMEWORK: THE CONFIGURATION OF CURE

To analyze the processes through which the 1937 and the 1948 experiments came to their respective conclusions, I use the concept of the “configuration of cure”. This concept draws on Canguilhem’s idea of cure as achieving a new norm of life. It also draws on science and technology studies’ insight that the quality of association that assembles multiple actors to make an object work defines the effect of the object.

In the book *On the Normal and the Pathological* (Canguilhem 1978 [1966]), philosopher Georges Canguilhem proposed a set of language for talking about therapeutics and scientific methods. Using pathology as his main example, Canguilhem argued that pathology had been rooted in clinical practices. And clinical practices were closely connected with therapeutics, a technique for establishing or restoring the subjective satisfaction that a norm was established. Therapeutics might be enhanced by science, but science alone was not enough to decide norms of life—an activity of debating with environment. According to Canguilhem, the pathological state, like health, is a certain mode of living. And cure is to be given new norms of life, instead of being brought back to a state of biological innocence.

Building on recent literature on science and technologies, I will discuss the quality of the association that defines particular technological objects’ effects. As pointed out in recent literature (Gomart 2002a and 2002 b; Gomart and Hennion 1999; Johnson 1995; Latour 1987; Latour 1999; Mol and Elsman 1996), for a scientific fact or a piece of technology to happen it takes an association of multiple actors. There might or might not be a designer or a core, for the association. A carefully designed network of machines, skills, and social relations may collapse
due to a missing element as tiny as a type of wood a “Gasogene” has to be fed (Akrich 1993) or a type of plug a photoelectric lighting kit depends on (Akrich 1992). On the other hand, a Zymbabwe Bush Pump that has a simple and flexible set of mechanics is capable of adapting to various situations (de Laet and Mol 2000). On some occasions the trick is to find a balance between flexibility and rigidity (Timmermans and Epstein 2010); on some others it is to be as strategic as in the way Louis Pasteur followed the hygienists (Latour 1988). On still others ambiguity is what makes the association work (Singleton and Michael 1993).

This does not mean that whether and how an association works is simply random. Instead, in every particular situation there is only a limited set of configurations of the association that would work. For example, rationality in science is an outcome of the process of knowledge production and is specific to particular science disciplines (Latour 1987). Along this line, researches find that different departments of the same hospital see different realities as relevant, and yet, in a hospital, clinical realities come before pathological ones (Mol 2003). Discussing the quality of the association is to explore specifically how multiple objects and actors associate with each other and with what effects. For example, methadone can be another addictive material not very different from heroin. But when used by medical workers willing to experiment and patients desiring freedom, it can be a “generous constraint” that allows a person to gradually break free from heroin.

Building on the above literature, the concept of the configuration of cure emphasizes cure as something that is defined contextually, rather than in the abstract. An object has a particular effect when an association of multiple actors is specified. The quality of this association matters in defining the effect of the material. Moreover, in light of the idea of cure as a way to give new norm to life, for a material to have the effect of a cure, the quality of the association might need
to include flexibility. For example, there might need to be willingness to tolerate a certain level of toxicity if the payoff is to cure a previously incurable disease.

Using this concept of the configuration of cure, the analysis below focuses on the respective associations specified by the two experiments on DDS. I begin by explaining the ideas of pharmacologists in the early 20th century, which informed the two experiments I will analyze. Then I examine the processes through which the 1937 and 1948 experiments came to their respective conclusions about DDS. I will show that the two experiments delineated associations with different qualities. Associated with different objects and personnel in different manners, DDS acted differently. In the 1937 experiment, DDS was associated with mice and streptococcal infections—a standardized set of objects used in chemothperapeutical experiments in the 1930s—and made comparable to other compounds. As such, DDS was a toxic material. In the 1948 experiment, DDS was associated with patients with an incurable disease, an experienced physician, and used only at a low dose. As such, it was a cure.

**THE IDEA OF CHEMOTHERAPY THAT INFORMED EXPERIMENTS ON DDS**

To contextualize the two experiments I will analyze, in this section I first illustrate the basic ideas of the first generation of pharmacologists, who were inspired by chemotherapy. Chemotherapy was a principle for drug invention taking shape in the early 20th century. The problem chemotherapy of the time stated and aimed to solve was: “Through what chemical compounds with specific affinity for certain infectious agents or cells could one act directly on the cause rather than on the symptoms of disease, in imitation of the antitoxins present in various serums” (Canguilhem 1988:65)?

Posing the problem as such was to propose a particular way of seeing and dealing with
disease. The idea of diseases as stand-alone entities with specific causing agents was articulated several decades before the advent of chemotherapy.\(^1\) Chemotherapy was proposing to substantiate this idea by using synthetic compounds.\(^2\) The hypothesis was that the selective affinities of synthetic compounds for certain cells could be used as a way of systematically finding useful compounds.\(^3\) Through these compounds that acted only on disease causing agents but not human cells,\(^4\) human beings would be able to act directly on the cause of diseases. In the words of Jim Johnson (a.k.a. Bruno Latour) (1995), human beings “delegate” chemical compounds to act on diseases. Promising to enable human beings to act directly on the causes of diseases, chemotherapy proposed to find substances that have fixed structures from which it was possible to deduce actions. This sounds like a classical actor-network project: to find an actor so that a network, composed of a series of elements with well-defined relations among them, would happen to the actor (Latour 1990; O’Connel 1993).

Will chemotherapy realize the proposition of a new way of dealing with disease using a synthetic compound that acts as an actor of a classical actor-network? In 1937 when Gladwin Buttle at the Physiological Research Laboratories of the Wellcome Institute was about to conduct a trial on DDS, this was the question he was trying to answer. Two years ago in 1935, Gerhard Domagk working at the Bayer laboratories in Germany had just published his research result claiming that Prontosil, a synthetic drug invented following the principle of chemotherapy, was effective against streptococci infections. Along this line, Jacques Tréfouël and his colleagues at the Pasteur Institute in France found that sulfanilamide was also active.\(^5\) These caught the attention of many pharmacological researchers, including Gladwin Buttle. Previously working in the tradition focusing on the extraction of active compounds from plants,\(^6\) Dr. Buttle was now to explore the territory of chemotherapy. Following chemotherapy’s principle of manipulating the
structure of compounds, Buttle chose DDS as the first compound after sulfanilamide and its allied compounds to try. This was the context in which DDS, today known as an anti-HD drug, was first tried. However it was the 1948 research by John Lowe working at the Leprosy Research Unit in Nigeria, instead of the 1937 by Buttle, that established DDS as a chemotherapeutic agent.

Did the 1937 research fail while the 1948 research succeed in establishing an actor-network based on DDS? This did not seem to be the case. Both were solid researches and each, with hindsight, was fruitful in terms of inspiring later research or application. I will argue that there were multiple DDSs, enacted differently by the 1937 and the 1948 researches. I will explain how this was possible for a synthetic compound. Following Dr. Buttle and Dr. Lowe, I will illustrate the 1937 and the 1948 “first-time throughs” (Garfinkel et al. 1981) of DDS. I will analyze the actual processes through which DDS became a chemotherapeutic agent. Particular focus will be on the relations among the elements that enabled DDS to act and the quality of the association among the elements. I will show that there were two different associations. These two associations overlapped partially. And yet it was the 1948 experiment, which saw DDS as a fluid material that could be manipulated, rather than as a core of a network with fixed principles, that released the characteristic of DDS as a cure.

DR. BUTTLE’S 1937 EXPERIMENT ON DDS

I. A Rational Move Following Chemotherapy

After the researches on Prontosil and sulfanilamide and its derivatives, in 1937 Buttle had in his laboratory some experimental animals, a few chemotherapeutic agents of known effects, and the streptococci strain “Richards.” In Buttle’s earlier experiment, Prontosil was not effective against
the strain of streptococci he was working on. However, he was more successful with using Prontosil against virulent strains—“Richards”—provided by physician Leonard Colebrook who worked on cases of puerperal sepsis. After this initial success he was encouraged to test sulphanilamide and its derivatives in pneumonia, meningitis, gonorrhoea, and intestinal infections, through which he established the value of sulphaguanidine (Buttle 1980). Now the question for Buttle was: based on knowledge of Prontosil and sulfanilamide and its derivatives, how to find more chemotherapeutic agents that are effective and safe?

Buttle chose to test 4,4’ diamino-diphenyl sulphone (DDS) and a related compound as his first move.

“After Domagk’s initial discovery (1935) of the therapeutic value of Prontosil in streptococcal infections of mice, and the further discovery by Tréfouël, Nitti, and Bovet (1935) that p-amino-benzenesulphonamide (commonly called sulphanilamide or sulphonamide P) was also active, a number of other compounds of this series have been tested, but in no case was there a striking increase in activity over sulphanilamide.”

“The present communication deals with two compounds of a different chemical structure” (Buttle et al. 1937:1331).

This was a rational move according to chemotherapy, which proposed to invent therapeutic effect by manipulating the chemical structures of compounds. Now that Buttle had fully explored sulfanilamide and its derivatives, it was rational to try compounds of different chemical structure to find desired effects. The structure of the compound he was looking at in the 1937 experiment was close enough to that of sulfanilamide to make it a probable chemotherapeutic agent, and different enough to give hope for “increase in activity over sulphanilamide.” Actually, this was a move so reasonable to researchers sharing the chemistry
language that, toward the end of the research, Buttle found that researchers at the Pasteur
Institute had independently conducted research on the same compound.

Figure 1-1. Molecular formulae of DDS and sulphanilamide

4,4’ diamino-diphenyl sulphone (DDS) sulphanilamide

Source: http://www.chemblink.com/index.htm

a. The chemical formula of DDS is C12H12N2O2S. That of sulphanilamide is C6H8N2O2S. The two
compounds differ in only one phenyl group (6 carbons and 4 hydrogens; expressed as a hexagon ring in the
molecular formulae). In this sense, they are similar. However, from the point of view of organic chemistry,
this difference means these two compounds are of different structures rather than derivatives of each other.
For discussions on the structure and naming of sulphanilamide and related compounds, see Northe 1948.

The compound Buttle was looking at was not unfamiliar to researchers. Chemists had
been able to synthesize DDS since thirty years before Dr. Buttle’s experiment.

“4:4’diamino-diphenylsulphone… (Fromm and Wittmann 1908), occurs in very long
colourless rectangular plates, m.p. 176°C. It is sparingly soluble (0.01 per cent.) in water at room
temperature, but more soluble (0.05 per cent.) in hot water” (ibid.:1331-32).

So DDS was a compound whose chemical structure was familiar to chemists. It was also
a compound whose chemical structure was similar to that of sulphanilamide, which made it a
reasonable candidate at the point of time when researchers were looking for their next step after
sulphanilamide and its derivatives. Starting from the chemical structure of DDS, Buttle described
DDS as an entity that was singular, stable, existing out there and could be synthesized per
request. He also described the logic of the research as to deduce desired effects from this entity
II. From Individual Entity to Association

Once Buttle started to work on the effects he expected from DDS, however, he stopped talking about the relation between structure and the desired effects contained within DDS. For it was not yet clear that what it meant to be at the same time effective and safe. From the myriads of ways to render the safeness and effectiveness of DDS tangible, Buttle chose the one that involved a comparison with sulphanilamide.

“Sulphanilamide is tolerated in 50 mg. doses given by mouth to mice of 20 gramme weight; these doses can be repeated daily in 25 g. mice infected with streptococci” (ibid.:1332).

In this single move two actors were introduced: sulphanilamide and mice of 20 gramme weight. When these actors were assembled in a particular way—50 mg. doses given daily by mouth of the mice—this was called the toxicity of sulphanilamide—the maximum amount of sulphanilamide the mice could take without being killed. This Buttle and his colleagues already knew from their previous study in 1936.

And then, “The 4:4’diamino-diphenylsulphone is tolerated in 5 mg. doses given by mouth; 2 mg. can be given daily to normal or infected mice, but daily doses of 5 mg. kill some of the animals” (ibid.:1332).

Keeping all the other elements in the assembly intact, Buttle replaced sulphanilamide with DDS in the assembly, and found that this made the maximum amount the mice could tolerate to change from 50 to 5. Therefore,

“…the diaminosulphone is about ten times as toxic as sulphana
ilamide when a single dose is given to normal mice (and about twenty-five times as toxic when the doses are given daily to
infected animals)…” (*ibid.*:1332; emphasis added).

To know the toxicity of DDS, Buttle positioned DDS and sulphanilamide on the same plane so that the toxicity of sulphanilamide, through the physical response of the 20-gramme weight mice, was passed to DDS. That the toxicity of DDS had to be known in this way demonstrated that the toxicity of DDS was variable and relational. DDS was not a stable and existing chemical portrayed in the opening paragraph of the research report. Neither did it possess innate properties waiting to be discovered. Before being fed into 20-gramme mice, DDS was not yet toxic. It was toxic only when taken by the mice in a way that allowed it to have a relation with sulphanilamide. The toxicity of DDS was composed of an intertwinement of sulphanilamide and mice with Dr. Buttle, who hypothesized that DDS was toxic and made it enter a set-up so that its toxicity could be known. It was something that emerged from this intertwinement of entities and practices.

### III. The Moment of Indeterminacy: Effects without Causality

To make the effectiveness of DDS tangible, Buttle again mobilized sulphanilamide, mice of 20 gramme weight, and the streptococci. The mice were made into groups of ten, “infected with streptococci ("Richards") intraperitoneally and treated with the various drugs, administered orally” (*ibid.*:1332).

After ten days, for each of the groups of mice the number out of ten mice surviving was counted. This simple action of counting turned mice—alive and dead—into a series of numbers. Since there were nine groups of mice, he got nine numbers: 0, 1, 1, 4, 4, 5, 6, 8, and 8. So there were variations among the groups: in one of the groups all the mice were dead and in the rest groups some survived. It worked. But we did not know yet what it was that worked. Everything
that could possibly influence the death or living of a mouse could be the influence for the mice having just gone through the experiment here. This was the moment of indetermination or coextension of actor-network theory. There were only effects, but no causality. The effects were coextensive with the mice, the streptococci “Richards,” and the chemical compounds, which were assembled by Dr. Buttle in a particular way.

The assemblage coextensive with the effects started to be differentiated into different elements when the numbers were linked with the experimental design and were turned into a table.

“Table I shows a comparison between the therapeutic effects of sulphanilamide and of …diamino-sulphones (ibid.:1332).” By saying so Dr. Buttle drew our attention to Table I located on the top of the same page of this sentence.

<table>
<thead>
<tr>
<th>Treatment (by mouth).</th>
<th>Haemolytic streptococci “Richards” I.P.</th>
<th>Approx. number of organisms.</th>
<th>Number of mice (out of groups of 10) dying on each day after infection.</th>
<th>Mice surviving 10 days.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Controls untreated</td>
<td>10^{-9} c.cm 10^{-7} 10^{-5}</td>
<td>2 130 13,000</td>
<td>0 2 2 0 0 0 0 0 0 0</td>
<td>6 1 0</td>
</tr>
<tr>
<td>Sulphanilamide--</td>
<td>10^{-5} 10^{-5} 10^{-5}</td>
<td>13,000</td>
<td>0 0 0 0 0 0 0 0 2</td>
<td>8 4 1</td>
</tr>
<tr>
<td>40 mg.: 1, 2, 3, &amp; 4th day.</td>
<td>4 mg. &quot; 0.4 mg. &quot;</td>
<td>10^{-5} 10^{-5} 10^{-5}</td>
<td>13,000 13,000 13,000</td>
<td>1 2 0 0 0 0 2 1 0 0</td>
</tr>
<tr>
<td>4:4’ diamino-diphenylsulphone--</td>
<td>4 mg.: 1, 2, 3, &amp; 4th day.</td>
<td>0.4 mg. &quot; 0.04 mg. &quot;</td>
<td>10^{-5} 10^{-5} 10^{-5}</td>
<td>13,000 13,000 13,000</td>
</tr>
</tbody>
</table>


a. Parts of the original table only.
In the table the numbers were made into three sets. In the first set, the numbers in the last column represented the mice receiving no treatment of either sulphanilamide or DDS—“controls untreated”—and surviving ten days. Linking the numbers with the administrations showed that the number of mice surviving decreased along with the increase of the number of streptococci injected. This linking of the number of mice surviving with the amount of streptococci injected into mice suggested a causal story: When the mice were infected with a $10^{-9}$ c.cm liquid containing two streptococci, 6 out of the ten mice survived. When the mice were infected with a $10^{-7}$ c.cm liquid containing 130 streptococci, 1 out of the ten mice survived. When the liquid was increased to $10^{-5}$ c.cm, which meant that it contained 13000 streptococci, none of the mice survived. This separated the mice from the myriads of influences that could possibly influence the survival of a mouse except one—the infection of streptococci. We now know that it was the streptococci, rather than any other factors, that were killing the mice. We also know the amount of streptococci that was able to kill both the stronger and the weaker mice—13000. Following Dr. Buttle’s action of arranging numbers into a table, we have witnessed the emergence of streptococci as a cause of death of mice.

In both the second and third sets, all the mice were injected with a $10^{-5}$ c.cm liquid containing 13000 streptococci, which, according to the causality just established, meant these mice would most likely die. However, in the table, the numbers told a different story. The second set of numbers showed that the number of mice surviving ten days increased along with the dose of the sulphanilamide: treated with 0.4 mg. of sulphanilamide daily, one out of ten mice survived. Treated with 4 mg. of sulphanilamide daily, four out of ten mice survived. Treated with 40 mg. of sulphanilamide, 8 out of ten mice survived. In the same way streptococci emerged as an actor
that killed mice, in the table sulphanilamide emerged as an actor that acted against streptococci.

“In the case of the diaminosulphone, doses of 0.4 mg. are as effective as 40 mg. of sulphanilamide, and doses of 0.04 are only slightly inferior; owing to the toxicity of the drug, however, doses of 4 mg. of the sulphone do not give such good results” (*ibid.*:1332). Again Dr. Buttle drew our attention to the table. This time he asked us to move our eyes to and fro between the second and the third sets of numbers. First, find the line of 0.4 mg. 4:4’diaminodiphenylsulphone, and find the number 8 that is at the end of this line. Then move to the line of 40 mg. sulphanilamide, and find the number that is at the end of this line. We find that the two numbers we just get are the same. At this moment, enacted as that *saving 8 out of 10 Mice infected with 13000 streptococci*, DDS enters the same plane as sulphanilamide. In this plane, the effect of sulphanilamide, known as a chemotherapeutic agent in the previous literature, is passed to DDS.

For the first time we are talking about the therapeutic effect of DDS. The effect previously coextensive with mice, streptococci, and DDS, is now attributed to DDS. Following the hands of Dr. Buttle, who made countings, grouped the numbers, and drew the table, we witnessed the ontological change of the assembly of mice, the streptococci “Richards,” and the chemical compounds. This assembly was first turned into a series of numbers, and then turned into a table in which sulphanilamide and DDS were foregrounded while mice and the streptococci were backgrounded. Parallel to this process, sulphanilamide emerged as an actor. And DDS emerged as a new actor which had gained its ability to act from the established actor sulphanilamide.

*IV. Attributing Causality to DDS*
DDS emerged as an actor with self-contained power at the end of the research. It was a chemical compound that was 100 times more effective therapeutically than sulfanilamide. However it was also 25 times more toxic than sulfanilamide. Expecting a center for an actor-network of chemotherapy, Dr. Buttle concluded that DDS was not suitable for use as a drug. At the end of the report of his experiment, he summarized the result:

“1. 4:4’ diaminodiphenylsulphone (diaminosulphone) is active in curing streptococcal infections of mice in doses of about one-hundredth of those required with p-animobenzenesulphonamide (sulphanilamide); it is, however, twenty-five times as toxic. The drug is not more toxic than sulphanilamide in normal rabbits or monkeys, except that it is more active in producing methaemoglobinaemia in the latter animal.

2. The corresponding dinitro compound (dinitro-sulphone) is not as toxic to mice as sulphanilamide and its antistreptococcal activity in mice is not inferior to that of the latter substance” (ibid.:1334).

**DR. LOWE’S 1948 TRIAL ON DDS**

*I. Chemotherapeutic Treatment for Hansen’s Disease*

Unlike Dr. Buttle, who took a scientific approach, Dr. Lowe built upon his expertise as a physician. He took risks in manipulating the doses of DDS and applying it to his patients. In contrast to Dr. Buttle’s rational moves, Dr. Lowe’s experiment was more in a bricolage style. A few years before Dr. Lowe’s trial of DDS in 1948, British medical circle had just started to be aware of the chemotherapy of HD. In the early 1940s at the Carville Hospital, a leprosarium in Louisiana, U.S., a chemotherapeutic agent “Promin” was found to be effective against HD.
was not the first time chemotherapeutic agents were tried on HD but was the first time a chemotherapeutic agent was found to be effective. The new treatment at Carville motivated some British physicians to also adopt Promin or related chemotherapeutic agents for their work, while some others remained suspicious and argued for the old way of using Hydnocarpus Oil distilled from the oil of chaulmoogra trees (Muir 1944).

This was the point of entry of John Lowe’s 1948 research at the Leprosy Research Unit of Nigerian Leprosy Service. As a supporter of chemotherapy, Dr. Lowe had devoted himself to proving that the chemotherapeutic agents were tolerated by most patients and that they were of value for both the more severe and the milder types of HD (Lowe 1950). But he was also aware of the criticisms that the chemotherapy of HD took a very long time (four years or even more) and that the treatment was too costly for wide use in poor tropical countries.

“The expense of sulphone treatment could be usefully reduced if a much more efficient and rapidly acting sulphone could be found, or if the sulphones could be made much more cheaply. A sulphone which would be both cheaper and more effective would be of enormous value” (Lowe 1950:145).

In search of such an agent that would improve the chemotherapy of HD, Dr. Lowe turned to DDS, a non-proprietary drug which could be made cheaply.

II. From Chemical Structure to the Therapeutic Level

This turn to DDS, though reasonable in terms of price of treatment, was surprising from the point of view of the theory for drug invention that brought DDS and Promin to the scene—chemotherapy. A decade ago in 1937 when DDS was first tried by Dr. Buttle at the Wellcome Institute, it was determined to be too toxic to be used as a medicine. The drug Promin, through
which chemotherapy was applied to HD, was produced exactly with the hope to be less toxic than its parent compound, DDS. Therefore, this move from Promin to DDS indicated that Dr. Lowe was investigating DDS with an approach different from chemotherapy, the very theory that defined DDS as a material that was bactericidal and yet too toxic, and Promin as more suitable for using as a drug than DDS.

“The question which this paper attempts to answer is: can it (DDS) be used in treating human leprosy with safety and with good therapeutic effect” (ibid.:145)?

Dr. Lowe thought, and hoped, that DDS could be used in treating human HD with safety and with good therapeutic effect. How was this going to happen?

An important feature of Dr. Lowe’s approach was to move from chemical structure to the therapeutic level.

“There seem to have been no attempts to determine the therapeutic blood-level needed in man…” (ibid.:145). “The question to be investigated is whether it is possible in man to produce blood-levels of DDS of this order without toxic effects” (ibid.:146).

There was a therapeutic blood-level of DDS in man. When there was this blood-level of DDS in man and, if at this level there was no toxic effect, then we could say that DDS could be used in treating human HD with safety and with good therapeutic effect. This proposition marked the difference between Dr. Lowe’s and Dr. Buttle’s approaches. As discussed above, Dr. Buttle aimed to find the therapeutic power associated with the chemical structure of compounds. Here Dr. Lowe saw DDS as something to be tinkered with. He assumed that there was some way to use DDS that was beneficial to individuals with HD. The focus was shifted from the chemical structure of DDS to the way DDS was used.

Dr. Lowe hypothesized that 1 mg. per 100 ml. was this therapeutic blood-level. He came
up with this number by inferring from the derivatives of DDS. He justified this inference by drawing on previous studies suggesting that complex sulphones acted by being hydrolysed to DDS.

“It is well-established by the experience of many workers that complex sulphones, given in doses producing a blood-concentration of the order of 5 mg. per 100 ml.—and often much less than this—are therapeutically active in leprosy. Most of this blood content is not degraded to DDS and is therefore possibly or probably inactive. We must conclude that the minimum therapeutic blood-level of DDS itself in leprosy is perhaps 1 mg. per 100 ml., or even less” (ibid.:146).

With this hypothetic therapeutic blood-level of DDS, Lowe set out to examine the core question of his research: “whether it is possible in man to produce blood-levels of DDS of this order without toxic effects.”

“At October to December, 1948, nine patients with leprosy were given DDS daily by mouth in small and slowly increasing doses, with careful clinical and laboratory examinations for signs of toxicity, and the blood-levels attained on different doses were examined. The daily administration was continued for 9 weeks. The daily dose was given all at one time” (ibid.:146).

“These results were striking. The first dose of 100 mg. gave a definite blood reaction for sulphone, though the blood-level attained was hardly measurable. Further doses soon produced a measurable blood-level; and when the dose rose to 300 mg. a day the blood-level averaged slightly more than the 1 mg. per 100 ml. which, on the grounds outlined above, is probably a therapeutic level. …The later stages of the experiment showed that we had a considerable margin of safety; the slight signs of toxicity at the highest dosage soon subsided when the drug was stopped” (ibid.:146).
To Dr. Lowe’s surprise, 300 mg. a day was enough to produce a blood-level of DDS averaged slightly higher than 1 mg. per 100 ml—the hypothetic therapeutic level. This was a very small dose considering that it took five to ten times of related compounds to produce this level of blood concentration. This was not something that could be pre-determined. Instead, explanations were sought afterwards and it was found that DDS was almost completely absorbed from the gut and was slowly eliminated by the kidneys.

Most importantly, during the nine weeks when 300 mg. of DDS was given daily to the nine patients, hemoglobin estimations, Schlesinger tests, liver-function tests, and clinical observations showed no signs of toxicity at the current dose. This of course did not eliminate the possibility that there were toxic effects that were not detected. But this at least assured that, based on available evidences, the present regime was safe.

III. From Entity to Effect

A second important feature of Dr. Lowe’s experiment was to focus on effect, rather than the entity. After knowing the dose of DDS necessary to produce a blood level hypothesized to be effective, Dr. Lowe went on to examine whether this level, just proved to be safe, was indeed therapeutic. Fifty patients with the “lepromatous” type and fifteen patients with the “tuberculoid” type were selected. The patients were treated with exactly the same regime as in the preliminary experiment: the dosage was 100 mg. a day for the first two weeks, 200 mg. a day for the following two weeks, and the standard dose of 300 mg. a day from the fifth week onwards.

After treating for several months, Dr. Lowe found in the lepromatous cases “slow but sure subsidence of activity of the leprous lesions, gradual shrinkage of leprous nodules and infiltrations, healing of lepromatous ulcers in skin and mucous membranes, and improvement in
the patients’ vigour and sense of well-being” (ibid.:147). In tuberculoid cases he found responses to the treatment as summarized in a table.

Table 1-2. DDS Treatment of Leprosy: “Tuberculoid” Cases

<table>
<thead>
<tr>
<th>Case no.</th>
<th>No. and diameter (inches) of skin lesions</th>
<th>Inflammation of skin lesion</th>
<th>Thickening, tenderness, and pain in nerves</th>
<th>Weeks before first visible response to treatment</th>
<th>Weeks before complete subsidence of skin activity</th>
<th>Total weeks of treatment to date</th>
<th>Persistence of nerve lesions</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Major Tuberculoid 8 (1-2)</td>
<td>+++</td>
<td>+++</td>
<td>3</td>
<td>20</td>
<td>40</td>
<td>Tenderness gone; thickening less</td>
</tr>
<tr>
<td>2</td>
<td>12 (2-6)</td>
<td>+++</td>
<td>++</td>
<td>4</td>
<td>20</td>
<td>36</td>
<td>Nil</td>
</tr>
<tr>
<td>3</td>
<td>About 50 (1-2)</td>
<td>+++</td>
<td>-</td>
<td>3</td>
<td>12</td>
<td>36</td>
<td>Nil</td>
</tr>
<tr>
<td>4</td>
<td>About 20 (1-12)</td>
<td>+++</td>
<td>+</td>
<td>4</td>
<td>24</td>
<td>36</td>
<td>Some thickening; slight tenderness</td>
</tr>
<tr>
<td>5</td>
<td>About 24 (3-4)</td>
<td>+++</td>
<td>++</td>
<td>4</td>
<td>24</td>
<td>36</td>
<td>Some thickening; no tenderness</td>
</tr>
<tr>
<td>6</td>
<td>12 (3-6)</td>
<td>+++</td>
<td>+</td>
<td>3</td>
<td>24</td>
<td>24</td>
<td>Nil</td>
</tr>
<tr>
<td>7</td>
<td>About 20 (1/2-3)</td>
<td>+++</td>
<td>+++</td>
<td>2</td>
<td>24</td>
<td>24</td>
<td>Ulnar neuritis still present</td>
</tr>
<tr>
<td>8</td>
<td>Over 50 (3-6)</td>
<td>+++</td>
<td>+</td>
<td>2</td>
<td>12</td>
<td>28</td>
<td>Some thickening; no tenderness</td>
</tr>
<tr>
<td>9</td>
<td>About 50 (1/2-3)</td>
<td>+++</td>
<td>+</td>
<td>4</td>
<td>16</td>
<td>20</td>
<td>Nil</td>
</tr>
<tr>
<td>10</td>
<td>About 10 (1/2-2)</td>
<td>+++</td>
<td>+++</td>
<td>2</td>
<td>20</td>
<td>20</td>
<td>Thickening less; no tenderness</td>
</tr>
<tr>
<td>11</td>
<td>Over 50 (1-3)</td>
<td>+++</td>
<td>+</td>
<td>4</td>
<td>Still incomplete</td>
<td>16</td>
<td>&quot; &quot; &quot; &quot; &quot; &quot; &quot; &quot;</td>
</tr>
<tr>
<td>12</td>
<td>Intermediate Tuberculoid</td>
<td>++</td>
<td>+</td>
<td>3</td>
<td>12</td>
<td>36</td>
<td>Nil</td>
</tr>
<tr>
<td>13</td>
<td>Innumerable (small)</td>
<td>++</td>
<td>+++</td>
<td>3</td>
<td>24</td>
<td>32</td>
<td>Thickening and tenderness almost gone</td>
</tr>
<tr>
<td>14</td>
<td>Minor Tuberculoid</td>
<td>+</td>
<td>-</td>
<td>3</td>
<td>12</td>
<td>36</td>
<td>Nil</td>
</tr>
<tr>
<td>15</td>
<td>Several hundred (small)</td>
<td>+</td>
<td>-</td>
<td>3</td>
<td>24</td>
<td>24</td>
<td>Nil</td>
</tr>
</tbody>
</table>


At this moment we know that it was easy to produce a blood level of DDS of 1 mg. per 100 ml. and that when there was this blood level, there were no signs of toxicity. Moreover, when there was this blood level, there were signs that the disease improved. What we know is a situation and the effects emerging from this situation. The situation can be specified in the form of a regime of DDS. This regime was recommended by Dr. Lowe to other workers of HD.

“A regime of oral administration of small doses, rising very slowly from 100 mg. a day to
the standard 300 mg. a day in 5 weeks, is recommended, treatment being continuous. This regime does not produce toxic effects of any consequence, and it will maintain a blood-level of about 1 mg. per 100 ml., which on theoretical grounds should be a therapeutic level in leprosy” (*ibid.*:149).

We did not know which actor was the one that was acting. And actually, we did not need to know. This was an important moment in Dr. Lowe’s trial, a moment of indeterminacy. In this situation created by a regime, DDS was coextensive with the body; to be more specific, with the blood of the body. It did not work in itself. Rather, it worked by being an element of an assembly that was known to the physician as a blood-concentration of 1 mg. per 100 ml. At this moment Dr. Lowe was able to answer the question he proposed at the beginning of his study by saying that it was possible to produce therapeutic blood-levels of DDS without toxic effects. What is noticeable here is that he had not approached his subject in terms of finding a substance that would cure. Instead, he pursued the possibility of producing a situation for the desired effects to emerge. What is important is that things work, not the causality among the elements composing the situation.

*IV. From Property to Enaction*

Dr. Lowe did see DDS to be special.

“The special properties of DDS are outlined. In vitro and in animals its antibacterial power is possibly the greatest of any of the sulphones” (*ibid.*:149).

However, that DDS owned a special power was not enough to make it a cure. It required trial and error efforts on the part of the physician to release this special power. Until physicians knew how to release DDS’s power, it did not work. Before turning to DDS, Dr. Lowe already
had twenty years of experiences of treating HD. He observed the skin, counted the lesions and measured their diameters. He also touched certain parts of nerve to see whether there was thickening or tenderness. He asked the patient whether there was pain, and how he felt overall. He knew the course of the disease and how it looked when it was better or worse.

Dr. Lowe, who knew about HD but had not been able to make most of the cases respond to treatment, believed that incorporating DDS in the treatment would set most cases on the path of becoming better. He hoped for DDS to work and designed the situation he thought in which DDS would work. Central to this situation was an old trick of the trade of physicians—dosing technique. At the same time when he tried to make DDS work, Dr. Lowe also prepared himself to be surprised by the contingences of the process of discovery. He was confident and yet he did not dictate. He opened himself to what happened. The effect of DDS was not predetermined. Instead it was something that was accomplished through the collaboration among a physician who was experienced in diagnosing and treating HD, HD patients whose physiological responses would be observed, and blood from the HD patients that allowed observations of the level of DDS. It was first a performance and then a competence. DDS worked only when the physician knew HD, believed that DDS would be helpful in the treatment of HD, and set up a situation in which his competence was passed to DDS.

Comparison with Dr. Buttle’s research further illuminates the point that the innate property of DDS is not enough to make it work. When DDS was enacted as an actor whose power came from its innate property, an actor suitable to be the core of a network, the network either failed or succeeded. When DDS was enacted as a physician’s tool, something to be tinkered with, the physician was able to turn his competence into the effect of DDS.

This did not mean that the property of DDS was totally irrelevant. It helped when Dr.
Lowe needed to have a hypothetic therapeutic blood-level to start with. The chemical structures of DDS and the related compounds provided the necessary information. Then again, it worked better only when it was asked for, when it served.

Dr. Lowe’s research discovered DDS as a helpful tool. From now on physicians treating HD do not need to figure out by themselves from the beginning. This does not mean that treatment for HD is merely handing out a drug. For DDS to work, the physician still needs to know the disease and know how to enact DDS.

“The main and in fact the only real necessity for DDS treatment is the supervision of a sound clinician who knows his leprosy. Proper clinical examination before and during treatment, and the regulation of treatment according to the findings, are all that is really needed. During the first few weeks of treatment a weekly examination is advisable; later, an examination fortnightly, monthly, or even less frequently may suffice provided the patient can refer to the physician at once if need arises” (ibid.:148-9).

V. From Chemical Principles to the Pathological States

“The physician can now feel absolute confidence that an active case of leprosy, no matter how severe, will respond to sulphone treatment; that the disease will cease to progress from the time when the treatment is begun; and that the lesions already present will slowly subside and the infection gradually die out” (ibid.:149).

Without treatment of any kind, there were still possibilities for natural improvement. However, in most cases, HD ran its long course and eventually reached the “burnt-out” state (Bushby 1958). With DDS, it was very possible that the disease would cease to proceed. The skin lesions and nerve thickening would very possibly go away. However, DDS did not reverse
deformities that already happened. So DDS did not act by bringing patients back to what they were before they had not had the disease. It acted by making mortality part of the reality that it facilitated. It helped bring a new norm to life with an acknowledgement that life was mortal.

The very attempt of trying a potentially toxic material as a medicine echoes this acknowledge of mortality of life. For a material to become a cure, it requires acknowledgement of disability or disfunction as parts of life. It also requires taking risks. Thinking in abstract terms, Dr. Buttle did not see DDS, a potentially toxic material, as a good choice for medicine. Acknowledging that being mortal was part of life, Dr. Lowe thought that it might worth a try. As long as DDS treatment did more good than bad overall, Dr. Lowe would see DDS as a cure. DDS did not act by being abstract chemical principles. It acted by being engaged in the specific pathological states associated with a particular disease. And the pathological states, despite relying on an experienced physician to recognize, always go back to patients’ life. Using DDS as a cure meant accepting mortality as normal, as part of the reality of life. It also meant as long as it made life better than before, it was worth the try. It might not be good enough if biological innocence was the norm. But it might be the best one can do if mortality was part of the norm.

THE CONFIGURATION FOR DDS TO EMERGE AS A CURE

Following DDS through the two trials, we have witnessed the emergence of DDS as two different actors. We have witnessed how the trials provided for themselves the natural accountability of DDS. In each of the trials, a moment of indeterminacy was involved. At this moment we knew certain effects were happening but we did not know how and why they were so. Only at the end of the trial were the effects explained for and the efficacy of the experimenter’s work became the efficacy of DDS. Both of the two trials involved a particular kind of
construction, the kind of construction because of which scientific objects are real (Garfinkelet al. 1981; Latour 1999). Through Dr. Buttle’s and Dr. Lowe’s constructions DDS became scientifically real.

The two DDSs emerging from the two trials were equally valid, and yet different. Both Dr. Buttle’s DDS and Dr. Lowe’s DDS were accountable—verifiable to members of the same community—in terms of the respective languages Dr. Buttle’s and Dr. Lowe’s communities use. Dr. Buttle came from the community of the first generation of pharmacologists directly influenced by chemotherapy. Equipped with the theory of chemotherapy, Dr. Buttle attributed the efficacy of a chemical compound to its structure. He enacted DDS as an actor whose power came from its structure. Such an actor was, like Pasteur’s bacteria or lactic acid, aimed to be the core of a network (Latour 1988, 1999). Also like many such well-designed networks, the network worked in an either-or manner. Dr. Buttle concluded that a network with DDS as its core was bound to fail since it was too toxic to the host of the pathogenic agent.

Unlike pharmacologists who work with chemical principles, physicians work mainly with symptoms. Employing the physicians’ dosing techniques, Dr. Lowe enacted DDS as a physician’s tool. DDS was one of the composing elements of an association that was called DDS treatment. But DDS was not rigid. It was something to be tinkered with. In certain situations there could be a moment at which the dosage was therapeutic but not too toxic. Dr. Lowe bet for this moment and made DDS work for this aim. DDS became a delegated actor that facilitated a norm of life the physician hoped to give to the patient.

CONCLUSION: IN SERACH OF A CURE OR IN SEARCH OF A DISEASE?

What is DDS and what does it do? It is more than one thing. When enacted according to
the principles of chemotherapy, it is a chemical compound that kills bacteria as well as the host. When a physician treating HD knows how to use it to the extent that it is therapeutic but not toxic, it is a tool for the physician to treat HD. In the first case, DDS is an actor with clear boundaries and competence. However, it is DDS constructed in the second case as a serviceable tool that works better as a medicine. The second case of DDS does not seek to replace the first one. Instead it seeks to coexist with it. In the manner Mol’s fluid coexists with an area and a network (Mol and Law 1994), DDS as a tool contains DDS as a powerful agent. It is at the same time rigid and fluid, a synthetic compound and a serviceable tool.

This study of DDS contributes to existing studies on what a cure is and what it does. In the cases of hypertension, prediabetes, and hypercholesterolemia, the pharmaceuticals facilitate thinking about diseases in terms of risk reduction rather than in terms of symptoms. Pharmaceuticals have the potential of defining the normal and the pathological (Greene 2007). The case of methadone provides an interesting contrast. As part of the treatment for drug addiction, methadone does not define what is normal and what is pathological. Rather, it is the personality of the patient that determines the direction of treatment. Methadone does not redefine or transform. Instead it helps to reveal (Gomart 2002a and 2002b). The two cases of DDS I have followed add a further complication to the relationship between medicines and disease. For DDS to get the identity of a medicine, the situation for it to work has to be contextualized in the specificities physicians and patients working on HD face. Interestingly, the inclusion of mortality as a part of normal is one condition for DDS to cure in the first place. It is a medicine only when, all conditions considered, it serves the ends of benefiting life with a particular disease. Acknowledging mortality as normal so that it cures, DDS is a provocative case of what a cure is and what it does.
However, DDS started to lose its fluidity when it was introduced to HD hospitals in other countries and proved to be effective there. DDS started to be used in the HD hospital in Taiwan in 1952. In the 1955 report on DDS treatment, a physician working in the hospital wrote: “At first, the dosage of DDS adopted here was according to Lowe’s 1950 publication. That is, starting from 100 mg daily and gradually increasing to 200 mg daily and finally to 300 mg daily. However, there were side effects such as lepromatous reactions, swelling of lesions, macules, and stomach ache. Therefore the dosage was adjusted according to Lowe’s report in 1951….Right now the dosage of DDS is 10 -15 mg per kilogram of body weight every week. For example, if the body weight is 50 kilograms, the dosage is 500 – 900 mg every week” (Losheng Sanatorium 1955:17). Although this physician was aware of the side effects of HD and adjusted the doses he used, he decided later to follow Lowe’s 1951 report. And the use of dose according to the body weight of individual patients became conventional.

DDS further lost its fluidity when medical understandings of HD started to change. With the advent of DDS, medical practices changed from one focusing on symptoms to one focusing on pathogenic agents. The encounter with physician occurred mainly at the beginning. Then the interactions were among the patient, the technician, and the Bacterial Index (BI) produced by SSS examinations. With DDS, treatments for HD came to focus on removing the “real disease” as opposed to the symptoms.

As a strategy of preventive medicine, DDS treatment targeted sick individuals as a way to prevent the incidence of HD in the population. The head of the HD Prevention Committee in Taiwan described the mission of the committee: “As to contagious diseases in general, the primary way to stop them is prevention. Treatments are secondary. However, because there have been no ways to cultivate the causing agent of HD, there have been no ways to produce vaccines
to actively prevent it. …Nowadays, medicine is highly advanced. If HD is treated early, it should be cured. So (in the case of HD) early treatment should be used as the way of prevention” (Losheng Sanatorium1963:6-7). In 1963, the HD hospital estimated that there were 8000 to 10000 HD patients in Taiwan. It also estimated, based on medical records it kept, that there were 3239 patients under treatment. The HD hospital concluded that the rest 5000 to 6000 patients were scattered across Taiwan. Accordingly, a nationwide case finding survey was necessary to find out the correct number of HD patients. Assuming that a mass treatment approach would be effective, the new disease regime aimed to put as many individual patients under treatment as possible (ibid.). It is this prevention program that I am turning to. In the following chapter, I will examine patients’ experiences of the prevention program.

Endnotes

1. Several authors (Canguilhem 1988; Latour 1988; Rosenberg 2007) date the conceptual change to diseases as entities by the 1860s. However their opinions differ in terms of the genealogies of the many conceptualizations of diseases around the time. Rosenberg sees pathological anatomy, physical diagnosis, chemical pathology, and studies of physiological function all pointed toward the articulation of disease entities that could be explained in terms of specific causal mechanisms (ch 2 of Rosenberg 2007). Canguilhem argues that the 19th century medical theories, especially the physiological model, remained an ideology and the goal of the program was achieved by routes different from those envisioned by the program’s authors (ch3 of Canguilhem 1988). Latour finds hygienists expecting specific mechanisms explaining for communicable diseases and having the expectations articulated by a strategic actor Louis Pasteur (Latour 1988).

2. Specifically, chemotherapy proposes to find compounds with selective affinity to pathological agents or cells by synthesizing and screening dyes. For a detailed description of the development of the idea and the relation of the idea to other principles of drug invention of the time see Sneader 2005. Also see Mazumdar 1974 for introduction of Paul Ehrlich and his work.
3. Canguilhem argues that chemotherapy’s idea of drug invention by way of inventing a dye means to “change the positions of the atoms in a molecule, to alter its chemical structure in such a way that its color can be read out, as it were, from its formula” (Canguilhem 1988:67). Canguilhem thus sees chemotherapy as a form of rationalism. See also Gomart 2002b in which the author conceptualizes pharmacology in the early 20th century as trying out a classical philosophical a priori which takes substances to have fixed structures from which it is possible to deduce actions.

4. In the original proposition of chemotherapy formulated by Ehrlich, the chemical affinities of dyes would do the trick. He supposed a diagrammatic correspondence among the chemical structure of a substance, its selective affinity for different cells, and its color (Mazumdar 1974).

5. Ehrlich’s assumption of the correspondence among the chemical structure of a substance, its selective affinity for different cells, and its color does not hold when it was found that sulphanilamide, a colorless derivative of Prontosil, was also active. Safeness and effectiveness of a compound, which used to be compressed into the color of the compound, now requires other ways to explain.

6. For a description of the different traditions of drug discovery in Germany and in France and England in the early twentieth century, see Sneader 2005.

7. After its invention, Promin was first tried in experimental tuberculosis and turned out to be effective against the disease. Since the pathogenic agents of tuberculosis and HD were closely related, the research report of Promin caused the attention of the director of Carville, himself previously a student of tuberculosis. For the process of adopting Promin at Carville, see Faget et al. 1942 and Faget et al. 1943.

8. Since the mid-1930s, when the effects of Prontosil and sulphanilamide were reported, chemotherapeutic agents had been tried on HD. See Faget et al. 1942; Faget et al. 1943; Kamigawa 1940 for some early efforts of treating HD using chemotherapeutic agents.
In this chapter, I analyze the body-biography trajectories of HD patients to explain expectations and fears of stigma patients still live with even after they were cured of the disease. Using interview data, I will show that the expectations and fears of stigma were a result of the interplay between the new medical understandings of HD and patients’ body-biography trajectories. The introduction of DDS as a cure differentiated between the “real disease” and the visible signs of the disease. Under this view, patients who were cured of the pathogens but still had lingering symptoms did not have the disease. However, to the patients, the disease was still real as a part of their body-biography trajectories. Still having deformities and disabilities, patients found it difficult to establish a new identity on the outside. In the end, partly out of the need for medical care and income, partly out of attachment to the patient community, many stayed. Still carrying visible signs and failing to resume social roles on the outside, patients thus expected and feared stigma—not stigma associated with the “real disease”, but stigma associated with their discredited aspects of identity.

In line with recent literature on stigma, this study on patients’ body-biography trajectories emphasizes stigma as a persistent predicament or dilemma. In his seminal study on stigma, Goffman (1963) argued that stigma is a relationship between an attribute and stereotype. Building on Goffman’s conceptualization, Link and Phelon (2001) specified the nature and consequences of stigma: stigma occurs when labeling, negative meaning, segregation, and status loss converge in a power relationship. Involving a social process as such, stigma has negative
consequences that are difficult to eradicate. People who have been hospitalized for mental illnesses are likely to expect and fear rejections. Thus they may act less confidently and more defensively, or may simply avoid a potentially threatening contact altogether (Link and Phelon 2001). These individuals face various negative consequences, such as more constricted social networks (Link et al. 1989), a compromised quality of life (Rosenfield 1997), low self-esteem (Wright, Gronfein, and Owens 2000), depressive symptoms (Link et al. 1997), and unemployment and income loss (Link 1987). Similarly, individuals with visible disabilities find that they constantly have to conduct “deviance disavowal” during first contacts, which is restraining for them to develop deep relationships (Davis 1964).

I also draw on the literature on body-biography trajectories. Studies on processes through which individuals enter chronic medical situations found that the trajectories of disease and biography operate and pull at one another (Strauss et al. 1985; Star and Bowker 1997; Timmermans 1998). I focus on the turning points in patients’ body-biography trajectories. By turning points I mean the switches in one’s life that govern changes between the regular sub-processes. The more regular sub-processes can be understood on their own and are programmed by multiple institutions such as school, marriage, and work. The switches are internal or external shocks that make an individual leap to a new steady trajectory (Abbott 2001). Focusing on the turning points means to focus on a person’s attempt to hook multiple trajectories up into a reasonable sequence. Drawing on this definition, I identified two main turning points in patients’ body-biography trajectories: the diagnosis, and the application of DDS. I will discuss how each of these two events constituted shocks to the regular sub-processes of patients’ body-biography trajectories. Then I will discuss how, following the turning points, individuals tried to hook multiple trajectories up or to leap to a new steady trajectory to obtain a reasonable sequence.
Below I analyze patients’ body-biographies before and after DDS. In line with the literature on body-biography trajectories, I will show that HD spilled over to many aspects of patients’ identities. Patients’ lives were intertwined with the hospital and the patient community so much so that when the new classification system defined them as cured, it was still difficult for patients to establish a new life outside of the institution.

I will also show that there were two different stigmata. Before DDS, the stigma existed as a relation between visible signs of the disease and a “real disease.” After DDS, the stigma existed mainly as a relation between the visible signs and a discredited identity. To be more specific, before the introduction of DDS in 1954, the main issue for HD patients was to deal with their disease as a discreditable feature. Patients had to carefully manage their self-presentation in order not to reveal their disease to others. When the stigma was too difficult to manage, patients might choose to be segregated voluntarily.

After the introduction of DDS as a cure, the main issue for the patients staying in the hospital or those who had disability or deformity caused by HD (in many cases, these two situations came together) was to deal with a discredited identity. Their disease, though arrested by DDS, had already “spilled over” to other aspects of their identity. Patients had established relationships with other patients, and had relied on pension as a source of income. What they had to manage was not to prevent others from knowing about their disease, but to prevent others from looking down upon them because of the aspects of their identity stained by the disease. The identity as an HD patient, ironically, sometimes became a convenient way to manage their discredited identity. However, the price might be to surrender engaging in negotiation for a less stereotyped identity—for example, to gain recognition for the many struggles between lives inside and outside of the hospital.
BODY-BIOGRAPHY TRAJECTORIES BEFORE DDS: HD AS A DISCREDITABLE DISEASE

In this section I analyze patients’ body-biography trajectories before there were DDS. I will show that a diagnosis of HD meant a serious disruption to one’s body-biography trajectory. Therefore patients tended to consider other possibilities than HD when bodily signs first appeared. Physicians shared this awareness of the implications of a diagnosis of HD. In a lecture that was later published in 1927, a dermatologist said that if three symptoms—lepromatous rash, loss of sensation, and swollen nerves—were present at the same time, then a diagnosis of leprosy could be made for sure. However, clinically, there were a lot of difficulties to make such a firm diagnosis. First of all, in most cases the three symptoms did not exist at the same time. Furthermore, the diagnosis would be painful to the patient, the family, and the society as a whole. Therefore he especially felt the stress to make careful diagnoses (Aoki 1927).

Most of the time, patients started to receive treatments only at more advanced stages. Even under treatment, the disease continued to progress. When the family was no longer able to afford the treatments or the stigma was too difficult to handle, the child would need to go to the sanatorium or almshouses. Patients went through several stages. They started by noticing bodily signs and treating these signs as consequences of a common cold or things not too threatening. After realizing that the signs did not disappear despite the various kinds of treatment tried, the patient or family members eventually suspected a link between the signs and HD. The time it took for patients and family members to accept the fact was influenced by whether there were other family members who had the disease, and the attitude of family members. In some cases,
the patient had not been able to accept the fact until after hospitalization. In the hospital, patients
might be surprised again when they realized what the disease was like for other patients.

I. The First Appearance of Signs
Recalling the start of the disease in their childhood or puberty, patients reported that they did not
know they had HD when they started to be sick. They found that they were developing certain
signs which they knew, only after a period of time, to be related with HD.

Mrs. P said: “We were preparing for the entrance exam for the junior high. During the
break we were asked by the teacher to run from the school to the beach and back. Other
children’s redness in face faded after a while. Mine didn’t. It lasted for several days.”

Mrs. T’s right hand lost skin sensations. She said: “I was in grade school. Whenever I felt
nervous in class, I had the habit of biting my hand. Strangely, I did not feel hurt at all.”

Mrs. Y described the first appearance of the bodily sign as such: “One day we were asked
to form a line. The teacher asked us to raise our hands to align with the shoulders of the person in
front of us. I was not able to raise this hand (pointing to her right hand). The teacher hit my hand.
He told my mother about this.”

These signs were found as minor disturbing of daily activities instead of symptoms per se.
At this point there were only signs, but not yet the disease. What was later known to be HD was
now redness in face, loss of senses, or disfunctioning of a hand. It existed on the surface level of
the body. It had a color and a shape, and caused some bodily feelings. It did something, but was
not yet an entity in itself.
It took months or years for the first signs to become something that felt more unusual (Bryceson and Pfaltzgraff 1990:11). So the state of being sick but normal could last for quite a while. The child still went to school or helped with work in the farm.

II. Explaining for the Signs

Explanations were sought after. Mrs. R’s mother took the child to Taoist temples first. Others saw doctors who practiced herbal medicine or western medicine. The explanations from these sources for the bodily signs varied. Mrs. H’s bodily signs were interpreted as the result of the infliction of a ghost: “At that time we did not connect the disfunctioning of my feet with the disease. Even though we saw signs in my ears and faces, we never thought of this. We asked everywhere and were told that it was because of the ghost of a woman who died with injustice. So we had Taoist rituals here and there.”

The doctor Mrs. R saw advised her mother to prick her using a needle when she was not paying attention: “He told my mother to prick me when I’m not paying attention. My mother didn’t want to do that. She told my grandmother about this. I overheard the conversation and was very afraid.” While Mrs. R’s mother is not willing to prick her child, the doctor Mr. L saw did not hesitate to do that to his patient: “He asked me to close my eyes. Then he pricked me with a needle. I didn’t feel it. Then he knew I had this disease.”

The connection between the bodily signs and the disease established by the medical professionals was not accepted by the family members automatically. Mrs. H received clinical examinations after much effort was invested in Taoist rituals. Her grandmother refused to accept the connection at the beginning, for her symptoms were not very obvious.
Established cases in the family facilitated the connection of the bodily signs with the disease. Mrs. Z’s father was discovered with HD and hospitalized accordingly when she was very little. After being notified by the teacher of the disfunctioning of Mrs. Z’s hand, Mrs. Z’s mother took her to a few temples. The mother came to the conclusion that she had HD and gave up treating her very quickly. Similarly, because of established cases in the family, Mrs. R’s mother came to accept the belief that her daughter had HD even without pricking her daughter or having her daughter’s symptoms confirmed by a doctor. Mrs. R’s uncle had lived with HD before she had the bodily signs. There had been a belief in Mrs. R’s family that the disease “wei zho buei wei bo” (染祖不染某; contagious among people who have blood relationships but not among people who have marital relationships).

In some cases, despite these previous knowledge or experiences with the disease, it was still difficult for the person and the family members to link the bodily signs and the disease. For example, Mr. H knew his brother had HD before he himself started to have modules in the skin. After starting to have the modules, Mr. H was given herbal medicine, which later proved to be ineffective. The therapist who prescribed the herbal medicine told Mr. H’s uncle that what Mr. H had might have been mafengbieng (痲瘋病; HD in Mandarin). Hearing this, Mr. H, who already was suspecting that he had the same disease as his brother, was relieved because it was not taigo (癩痾; HD in Taiwanese). It was only after another period of time that he started to suspect that mafengbieng and taigo were referring to the same thing. Mr. H then consulted several doctors trained in Western medicine, but got different answers. After visiting the HD hospital, where he was told that he had the disease, it took him another period of time to really accept that he had HD. Similar as Mr. H, several other interviewees and their family members started to suspect
something more serious only after the original treatment was ineffective or when the disease became worse.

Unlike the perception of the bodily signs, to explain took planned activities, resources, a caring figure, and specializations. A caring figure in the family, usually a female elder member, was involved. She fetched information from her network and took the child with the bodily signs awaiting explanation to various specialized people who might be able to provide a helpful interpretation. These activities—involving a caring figure in the family, specialized knowledge, a needle, pricking, and trying various treatments—collectively established a connection between the bodily signs and a disease. At this point HD was no longer something that existed only at the surface level. It was something that dwelt inside of the body and required further action.

**III. Denying and Accepting the Diagnosis**

Patients and family members tended to deny the diagnosis of HD until the family had no money to afford treatments for the patient or the stigma was bigger than the family could manage. At these points, patients and family members accepted the diagnosis of HD and that the family had to let go of the child. In some cases, only family members accepted the diagnosis. The child did not realize what the implication was until they were hospitalized and were told by other patients what the disease was like.

The disease itself did not directly lead to institutionalization. The families invested a lot in the medicine. Mrs. R said: “The revenue of my family from harvest was all invested in the medicine I took.” Mrs. H’s grandmother sold lands and in the end sold their house. Certain daily rounds of the family and of the person were rearranged for HD. Mrs. R said: “I had a dose each day. One dose was to be cooked twice. So I had the medicine twice a day. I took the medicine
until I came here at about 30. I also took herbal powders, which was taken with wine. It is said that wine can counteract the disease.” Mrs. H also took herbal powders. Instead of taking it with wine, she took it with the blood of eel.

Whether receiving herbal medicine or Western medicine, patients tended to treat their own disease at home rather than going to the sanatorium. Mrs. R was already crippled when she was a child. Unlike many other young women of her generation who got married in their early twenties, she lived with her family until 30 because of HD. Despite financial difficulties, Mrs. R’s family had supported her. When treating her disease at home, she lived with her mother and younger brother and the three relied their living on a piece of farm. Mrs. R recalled: “I had rashes all over. They were red. My mother took me to the doctors everywhere, the Han doctors. I never recovered. Then she took me to a town nearby to see a Han doctor. He was such an expert. He suggested pricking me with a needle to see whether I notice it…. But the Han doctor was an expert. I had the herbal medicine for a while but did not get better. Twice a day. I had it until I came here when I was almost 30.” Mrs. R commented on the disease: “It was really serious. The revenue from the farm was all spent on the medicine for me.”

Coming from a more well-off family, Mrs. H had a similar experience. Her family tried to keep her until the family could not afford to. She lived in a spacious two-story house with her family when she was a child. The house and lands her family owned were all sold because of the disease. Mrs. H said: “To my grandmother, as long as there are people, there can be money. It’s fine not to have the house and the lands. Those can be earned again when the disease is cured.”

At the same time, some other daily rounds were rearranged so that life went on in spite of HD. Mrs. R said: “Despite having the disease, I still need to work. I worked until this foot (raising her right foot) was disabled and I was not able to walk. I worked at home, raising
chickens and pigs and growing sweet potatoes. The leaves of sweet potatoes can be used to feed pigs. Everyone worked outside. I’m the only one at home.” Mr. L helped with work in the farm. He said “when we were harvesting water bamboo, none of our neighbors dared to come close to us.” Mrs. Z was locked in a barn by her mother so that visitors of the family did not find that the family had a child who had HD.

The efforts to counteract the disease and to integrate the disease into life entailed dilemmas for the family and for the person with the disease. Both the family and the person with the disease were caught between rearranging life to accommodate the disease and preventing life from deviating from the expected trajectories too much. Life needed to go on. The family needed to have revenue, to maintain relationships with other people, and to stay integral. A child with a rare disease jeopardized these aspects of life. These arrangements made to allow life go on in spite of the disease entailed loneliness and shame. Being prevented from certain aspects of life one used to lead or expect to lead, the person was made a disqualified social member. HD started to become a discrediting feature for a person.

Hospitalization, a previous undesirable choice, now appeared to be viable, for it meant technically competent help. Moreover it meant that the sick person would no longer be a burden of the family. Several of the patients said they became hospitalized voluntarily. Even Mr. H, who was forced to come to the sanatorium by the police who appeared unexpected one day at his home, said he followed the advices of the medical professionals voluntarily when in the hospital because he tried to get well as soon as possible.

To change the context for counteracting the disease entailed a process of working through the dilemma: keeping the loved one in the family and making life difficult; or letting the loved one hospitalized in exchange for the possibility of long-term welfare. The process of working
through the dilemma involved acquiring information of the sanatorium, realizing the impossibility of managing the disease at home, and making sure that hospitalization was not too unbearable for the child.

Some patients started to perceive the reality they faced only when among other patients. In the train headed for the sanatorium, another patient, upon seeing her having food provided in the train, told Mrs. Y that he lost all of his appetite because of being worried. Mrs. Y also found that some of the individuals in the train were old patients returning to the sanatorium. Brought with her these questions, she asked another young woman whether she would be cured and be able to go home. The young woman replied: “If the disease is treatable, why should they build such strong houses?” Realizing that he or she had lost what he or she was familiar with, the patient was left lonely and distressed.

IV. Losing and Giving Up Relationships

Patients started to lose relationships after the symptoms were linked with the disease. Patients and family members started to acknowledge that it might be HD, a disease with serious consequences. When the situation was too difficult and institutionalization became an option, patients and family members further reshaped the social relations they retained. Patients underwent a conversion of identities as they were being institutionalized. At home, the family members continued to conceal the fact from their communities. Sooner or later, patients found they lost all relationships.

Along with the acceptance of the disease, the sick person was exempted from certain social roles and the related responsibilities. The doctor usually advised that the child withdraw from school. The parents changed their expectations of the child. The sick person also distanced
him or herself voluntarily from previous social roles in order to avoid social encounters that might cause anxiety. After linking the symptoms with the disease, the sick person interpreted social encounters from the newly adopted perspective. Mr. H, for example, started to have symptoms on his face when he was a teenager and was working as a barber. However it was only after he accepted that the symptoms meant HD that he saw encounters with his customers as troubling. When customers asked whether he had acnes, he answered yes but felt uneasy. Not long after acknowledging the disease did he quit his job and stayed at home.

Gradually, patients found family members stood on the same side with medical workers, out of fear of the disease or inability to protect them. Mrs. Y remembered her parents discussing her disease at night when they thought she was asleep: “My father told my mother that he had to ask the public health bureau to pick me up. He knew what kind of disease I had.”

V. Building Relationships in the Hospital

Despite losing previous relationships, the individuals were patients for just a while. They established relationships with fellow patients in the hospital. Upon entering the hospital, he or she might be scared by the scene in front of her. What Mrs. Y remembered upon arriving the sanatorium was that a lot of people with swollen skin squatted and bathed themselves under the sun. The loneliness and estrangement was in time replaced by a sense of belonging. Mr. K said that he actually felt more comfortable when being with other HD patients. He said he and fellow patients would sometimes joke at each other: “You have mahong, I have mahong, too.” Mrs. Z said: “There are four kinds of leprosy. The skin type, the neuro type, the lepromatous type, and the immuno type. Just like there are many kinds of cancer, and yet they are all cancer, so there are many kinds of leprosy.” This conclusion of Mrs. Z, which was based on patients’
observations of each other, might not be in the same line with the understanding of medical professionals. But the conclusion the patients drew reflected the base upon which they developed a sense that they were people of the same kind. They also shared the memory of being treated with Chaulmoogra oil. Mrs. Z received the oil on her face and body. Mrs. Y received it on the butt. Both remembered the pains associated with the ulcer resulting from the oil injected under the skin.

A range of roles developed in the community due to the many human needs that the hospital failed to take care of. First, there were the roles developing out of care taking. The basis for taking care of fellow patients can be as random as living in the same room or having the same time schedule. The form of this kind of care taking could be casual. But the care taking relationship could become more regular or involve money. Mrs. Z remembered she was usually responsible for shopping for others on the outside. She took up this role because she was a child and outsiders seldom became suspicious of her. There were also people who washed the clothes for others in exchange for money. There was a couple who ran a vendor cart in the hospital. The convention of having a place for shopping in the hospital was so lasting that, after the hospital was renovated, many patients persuaded the couple to continue selling vegetables at the backdoor of the building. The couple thus restarted to sell vegetables, which was at the same time a business and a form of taking care of other patients. To reconcile the needs of the patients and the feasibility of the business, most of the goods they sold were ordered beforehand by the patients.

Second, there were also obligations developing from the organizations in the community. Take the church, for example, there were the more formal positions such as the elder, the deacon, and the accountant. There were also the positions based on talent, such as English translator,
leaders of the choir and choir members. In addition, there were those who volunteered to cook, clean, open the door of the church, or run the bell before the gatherings. Whether the obligation was formal or volunteer, people took their obligations seriously. Actually, those who earned reputation by taking care of others or holding a position in the church usually found themselves speak on behalf of the community.

In sum, before the introduction of DDS, HD suggested a situation that would somewhat inevitably deteriorate in time. In most cases the person ended up losing all the relationships and being segregated in a sanatorium. It was unfortunate for a person to have the disease. But he came to realize that it was outside of the realm for individual efforts. As time passed, many patients were able to rebuild relationships in the patient community.

**BODY-BIOGRAPHY TRAJECTORIES AFTER THE OUT-REACH PROGRAM: HD SPILLING OVER TO OTHER ASPECTS OF IDENTITY**

DDS started to be used in the HD hospital in 1952. This changed the prognosis of HD. However, being officially considered as cured constituted another disruption to patients’ lives. Despite being cured of pathogens, patients continued to suffer from lingering symptoms of HD. This discrepancy between medical understanding and illness experiences became even more obvious after 1962, when HD no longer required segregation.

From the viewpoint of the hospital, after receiving the treatment, patients eventually became uninfectious and could be discharged. They stayed in the hospital simply because they had nowhere to go to. From patients’ viewpoint, however, this was not such a smooth process. Instead, this was a process of disruptions and adjustments. Moving in and out of the hospital in search of an identity that fitted their illness experiences, patients made much effort to reshape the vision they had on their lives and rearranging or maintaining relationships they had.
I. A Change in Prognosis

Along with the introduction of DDS, the HD hospital started to make the patients into cases and to move them through. The hospital adopted a new way of registering the patients who had already lived in the hospital. Since 1954, the hospital conducted periodical SSS examinations for each of the patients. To do the examination, a technician would take smears by making small cuts in the skin of patients and then observe the smear under a microscope in order to decide whether and how much of bacteria existed in the patient. Depending on whether the bacteria existed, the hospital gave follow-up examinations at different intervals (Losheng Sanatorium 1955). This introduced a timetable for patients. Previously, there was no such timetable towards discharge. Patients simply were expecting living in the hospital until death. The introduction of DDS brought a change in prognosis.

However, patients did not recover from their illness according to the timetable. There were several reasons. Some did not take the drug because of lack of hope; they simply gave up hope after having tried many treatments in vain. Some gave up in the middle of treatment because of side effects of the medication. Still others were dubious and said they would take it after it proved to be effective and safe for others.

Mr. K was one of those who did not believe in the change DDS would bring about. He talked about when DDS was first adopted in the hospital:

“I was gambling every day. Otherwise I was thinking about going home all the time.”

There were side effects related with taking DDS, for example anemia, stomach ache, and lepromatous reactions. When these happened, patients made calculations between the pains they were experiencing and the possibility of improvement.
To some patients, the suffering they were undergoing at the time of treatment outweighed the promise of the treatment. A patient said:

“I had stomach aches after having DDS. So I did not want to take it. They asked us to take it in front of them. I put it in my mouth and spat it out after walking away.”

In addition to stomach ache, DDS treatment might also stimulate the type 1 lepromatous reactions. A textbook described this reaction as such: “The first (type 1) is cellular hypersensitivity and often, but not invariably, accompanies an alteration in the degree of cellular immunity exhibited by the patient, whose disease then undergoes a corresponding shift along the spectrum. It follows that reactions of this type occur in patients with borderline disease (BL, BB, BT) whose immunological status is unstable. The change in cellular immunity of the patient may be in either direction. The term reversal is used for an increase in immunity and a shift towards the tuberculoid pole and the term downgrading for a loss of immunity and a shift towards the lepromatous pole. Reversal commonly follows treatment; downgrading only occurs in a patient who is not receiving adequate treatment and is often precipitated by puberty in the male and pregnancy or parturition in the female” (Bryceson and Pfaltzgraff 1990:115).

As pointed out by the textbook, according to immunological theories, the type 1 reaction could signify a reversal or a downgrading process underlying the disease. However, for patients who were having the reaction, there was no way to differentiate between these two. When the type 1 reaction was stimulated by the DDS treatment, it simply felt the same as when it was taking place before accepting the treatment. What was sure was that the reactions were painful.

**II. Contested Endpoint**
The DDS treatment itself was a process that took time and efforts to occur. Medical workers and patients gradually came to have different opinions on when the treatment should end. Mr. L talked about his experience of taking DDS:

“After taking DDS my swellings in the face went away. Then my face was full of wrinkles. When I visited my village I was called agong (grandfather, or elderly man). I was in my early twenties and I was referred to as an agong!”

Mrs. J took DDS at home at first, but chose to be hospitalized afterwards. She talked about the period of time when she visited a local leprosy clinic at the interval of several weeks:

“Every time before I went to the clinic the disease happened. I was too nervous about the trips to the clinic.”

“My mother went the clinics with me. Each time we took the earliest train to the town and the latest one back. Then my brother came to the train station to pick us up. There were also buses between the town and our village. But we did not want to take the buses. In the buses everyone is in the same space. People would ask us where we were going.”

DDS treatment was not just applied to an abstract disease. DDS treatment was applied to persons in particular place and time, with relationships with other people. Thus the treatment needed to be arranged with efforts to accommodate the fact that village people knew each other, and that the traffic between the village and the town was arranged in a certain way. All these made DDS treatment something disturbing to one’s everyday life in childhood community. So much so that in order to be treated, one’s disease became worse. It turned out that the way DDS treatment was applied was itself a complication to its efficacy.

Medical workers decided whether patients were ready for discharge based on their bacterial examination results. However, in many cases, during the treatment patients developed
disabilities or deformities. According to a doctor working in the HD hospital during the 1980s, in average it took five years for the results of bacterial examination to become negative (Weng et al. 1990).

For certain patients, especially those who had serious disabilities or deformities, it was simply unintelligible to accept the official classification of being cured. They insisted that their disabilities or deformities were reasons for them to receive medication and stay institutionalized.

A patient said: “The doctor told me that I don’t have bacteria. How is that possible? Look at this [pointing to the ulcers on her foot]. If I don’t have bacteria how could I get the wounds?”

There was also the issue of relapsing. The regime of DDS treatment adopted at the hospital provided a way to define new case: “Relapses taking place during the intermittent treatment or after the treatment is stopped are regarded as new cases” (Losheng Sanatorium 1955:19).

However, to an individual whose HD relapsed, she was not getting another HD. Instead, she experienced a worsening of a disease she had had. Mrs. Y was one whose HD relapsed after she stopped taking DDS for a while. Mrs. Y moved to a southern city with her husband, whom she met at the hospital, in order to pursue a life on the outside. After living on the outside for twelve years, she returned to the hospital because of having symptoms of HD. She felt more comfortable receiving the treatment in an environment where she did not have to conceal her disease. Moreover, to Mrs. Y, family members might in some aspects not as supportive as fellow HD patients: “Our relatives did not know that we were very stressed when living on the outside.”

Still having lingering symptoms or fearing relapse, quite a few of patients had requested DDS for several decades. Some were still taking DDS occasionally at the time when this research was conducted. The endpoint of treatment was contested.
III. Separation: Between Inside and Outside

In response to the vacuum of meaning of their illness, some patients moved out, some stayed. The decision involved a weighing between multiple values: relationships with fellow patients, resources and services one was entitled to while living in the hospital, and freedom from the stigma associated with the disease. For the patients, most of whom did not have skills to find jobs on the outside, leaving the hospital meant to lose relationships with fellow patients and resources provided by the hospital. As a result, many chose to stay.

Patients made effort to establish connections with outsiders. Since the early 1960s, the hospital started to encourage patients to find jobs on the outside. Patients also exchanged job information. However, patients found that they had not socialized in the work culture on the outside. They did not own the skills and networks necessary to join the outside world. They only had the skills they already had before entering the hospital or those that they learned in the hospital. Mr. H was a barber before he entered the hospital. He continued to work as a barber. He also learned to play saxophone by joining a band organized by fellow patients. Sometimes they got jobs of playing at funerals on the outside. At the same time, in order to earn more money he worked as a dog breeder and sold dogs. None of these, however, helped him to make living without the relationships established in the hospital. Some other individuals sold foods or food materials, or did domestic work for other patients. For them it was even more important to rely on fellow patients as customers. For the patients, during the time they spent in the hospital, the outside world had become one in which they did not fit.

There were not too many choices for the patients in terms of job choices. Some chose to take up part-time jobs that required physical labors. Some chose to run small businesses using
money borrowed from fellow patients. There were also people who took up janitor jobs in other hospitals. Few of them made it to cut entirely the connections with the hospital. Most patients still depended on fellow patients for funds, information, and friendships. In particular, patients needed a reference to explain their disabilities to the employer, and to emphasize that the disease they had was not infectious after treatment. Take funeral bands for example, patients got jobs through Mr. H, who was in contact with an owner of a funeral business. Patients thus relied on connection with Mr. H in order to get jobs to play in a funeral band.

In addition to the challenges common to part-time jobs and small businesses, such as instability, patients encountered physical and psychological challenges that were peculiar to them. Working at a construction site or as a janitor could cause various wounds to the patients’ body, and worsened the disabilities they already had. Moreover, patients had to hide the connections with the hospital from people they knew in the work settings. They avoided letting their coworkers know where they lived; they also lied about the disabilities they had. All these added to the stress they already faced.

Patients often found that previous family members were not able to provide support. Some found that family members were simply occupied by their own business or saw them as redundant.

A patient said: “My parents passed away. I only have two brothers back home. They each had their own family. There were no reasons for me to rely on them.”

Mrs. Y and her husband were not able to find roles in their original family. During the period they stayed in the hospital, the family changed a lot and they did not feel very comfortable to stay with them.
The hospital served as a safety net. Patients relied on the hospital for accommodations when they searched for jobs. The pension for institutionalized patients, despite being scant, served as a steady and important source of income for patients, particularly because they were able to find only part-time jobs. Patients also encountered physical challenges that were peculiar to them. As already mentioned, working at a construction site or as a janitor could cause various wounds to the patients’ body, and worsened the disabilities they already had. Patients then needed medical workers whom they can access conveniently.

Not being able to leave the hospital and yet feeling the need to distance themselves from fellow patients, patients found themselves living in separation from bigger society. At times, the more patients tried to establish connections or to acquire positions on the outside, the more they were connected with the patient community in the hospital.

**IV. Status Loss: HD as a Defining Feature**

Establishing new relationships with outsiders were challenging. The symptoms patients had, such as deformities of facial parts, hands, and feet, and ongoing ulcers in various parts of body, were easily visible. Deformities of facial parts included paralyzed eyelids, indented nose, and swollen earlobe. Individuals having paralyzed eyelids did not close their eyes and tended to have tears. They did not have eye contact easily, and their tears did not denote emotions they had. Deformities of hands and feet, likewise, hindered certain interactions. When eating in group, individuals having hand deformities needed to rely on those with no such deformities to serve them food. Patients thus faced the dilemma between not enjoying the event and risking being seen as an inappropriate person. It took time to strike a balance in an event whose etiquette was taken for granted by the majority of society members. Because the symptoms hindered
interactions in various ways, they made patients constantly aware of being discredited during encounters with various outsiders. During the time pursuing a life on the outside, Mrs. Y found that a comment from a neighbor on her ability to handle house chores despite deformities in her hand would make her angry. Like the stigmatizing labels talked about by Goffman (1963), the symptoms suggested that individuals having the symptoms were different from others in the category of persons available for them to be, and of a less desirable kind.

Patients developed certain strategies for avoiding embarrassing situations. They kept the connections with outsiders to be purely functional. For example, they did not visit outsiders they knew at work at those people’s homes so that they did not need to invite them in return. They also refused to let people give rides to them.

Patients felt comfortable being with taxi drivers, funeral band musicians, prostitutes, gamblers—other groups who were also stigmatized in one way or another. These individuals came to the hospital and became part of the community, serving roles that were not fulfilled by patients. For example, a taxi driver was trusted by the patients because he did not look down upon the patients. This taxi driver ended up serving the majority of taxi needs of the patients.

The patients found that the relationships in the patient community were not accepted by members of their original family. Family members felt bewildered that patients established relationships with each other in the hospital. Assuming that the hospital was not a normal setting for normal relationships, family members felt disappointed by that the patients did not try harder to live on the outside. Mrs. Z’s elder brother questioned her many times: Why can’t you move out of the hospital? What is it so good about living there?

The lingering symptoms gradually became a distinctive feature of the individuals. Patients chose to stay in the hospital rather than returning to their childhood communities for
various reasons. Moreover, the lingering symptoms varied in terms of their location in body and
the degree to which they influenced lives. But the lingering symptoms, more than other features,
defined the individuals. People living nearby the hospital avoided getting into contact with HD
patients in a brute manner. They refused to have business transactions with the patients. If they
had to, they conducted symbolic behaviors such as avoiding receiving the money from the
patients’ hands. They also prevented their children from playing with children of HD patients.

On the other hand, various outsiders can easily approach the patients. Churches and
philanthropic groups came to help. They were surprised that the patients, like themselves, had
friendships, spouses, or children. Knowing that patients had established various relationships in
the hospital did not make the outsiders see the patients as social equals with themselves. Instead,
they tended to see the patients as needy individuals. A recurrent theme in the pastor’s sermons
was how lives were difficult because of segregation. At funerals, the pastor talked about the
deceased person’s life in a framework of being ostracized because of the disease, and yet saved
by religion.

This emphasis on the lingering symptoms as a defining feature became more obvious as
the patients outlived the tenures of medical workers. Coming out of school with general medical
trainings, the new medical workers were surprised by the existence of HD patients when they
first came to the hospital. Having no appropriate formal categories to classify the patients, they
inferred that the patients suffered from aftereffects of HD.

The hospital strengthened HD as a defining feature of the patients by redefining its
mission in the mid-1980s. As a result of an annual meeting, the HD Prevention Committee
included the accommodation of old, frail, and homeless patients as one of its main objectives.
The inclusion of this mission was different from the mission when DDS was first introduced, which was to free all HD patients from being segregated (Taiwan Provincial Government 1986). This inclusion of accommodation of patients as its objective was an action to obtain legitimacy on the hospital’s part. It is common for service-providing institutions to encounter “cyclical legitimacy crisis”: Organizations are often created to address a particular problem and is supported by the community because of shared values. As time passes, the community takes the organization for granted. The organization starts losing its legitimacy. When the community recognizes that the organization has not “solved” the social problem, the organization has reached a crisis point. To survive, the organization redefines its commitment to match the community’s understanding of the social problem. If this is done successfully, the community re-legitimizes the organization and the cycle begins again (Hasenfeld 1972:11). The existence of the patients suggested a result that was incongruent with the hospital’s goal of discharging all the HD patients. By redefining its objective, the hospital found a way to possibly obtain its legitimacy as an organization that provided services for HD patients.

V. Attributing Accountability to the Disease

Living with an awareness of stigma, patients felt the need to maintain symbolic boundaries with fellow patients. They developed strategies such as pretending not to know each other when running into other patients on the outside. They were also sensitive about children’s occupations. Having children who were able to find a decent job on the outside strengthened a patient’s self-esteem.

Even more importantly, patients expropriated their disease as an explanation for hospitalization. Patient selected from pieces of scientific beliefs and medical practices they were
exposed to and made these into mutual supporting stories. As HD patients, they had acquired
knowledge about the physical signs and certain classifications of the disease. In order to justify
the fact that they had lived most of their life in the hospital, the community members subscribed
to the beliefs about the causative agent. On the other hand, because of the stigma related with the
disease, they emphasized that they did not carry the causing agents now. A recurrent theme in the
narratives was that “we used to carry the bacteria but not now.” When encountering outsiders for
the first time, patients often emphasized that the disease was once infectious, and yet they had
had negative bacterial examination results. The community members also mentioned a lot that
“our children here do not have the disease.” The idea of the causative agents was thus drawn
upon only for explaining their staying in the hospital.

Drawing upon the disease allowed patients to account for their prolonged
institutionalization. Mrs. Y said that her body was not really for working as a cook on the outside;
not to mention that she burnt two of her fingers while working. Mrs. P commented on her and
her husband’s staying in the hospital: “We don’t stay here because of the monthly money. We
need treatments.”

Patients framed their living in the hospital in terms of rights and responsibilities. The
responsibility was to conform to the house rule of the hospital, such as letting the staffs know
where they lived, and to receive the yearly bacterial examinations. The right was the entitlement
to the monthly pension, a room, and free medical service.

The mutual supporting stories are told among the community members, usually when
talking about a sick or deceased friend. On an occasion in which Mrs. H was talking with two
other female patients about the children of some other community members, a seemingly out-of-
context comment was that none of the children had the disease. The implicit message here was
that even among the community members, the patient identity was not taken for granted and instead was maintained and renewed in everyday interactions.

The mutual supporting stories were not something the patients shared with their children. Mrs. Z, for example, had never discussed the hospital or the disease with her children. She said: “We didn’t talk to them about this and they didn’t ask either. When we moved back (to a house owned by the church in the hospital) they found that we were familiar with people here. Whether they knew or not, we didn’t ask….We just told them it’s a house owned by the church. Their father served in the church. And we moved back in the house also for taking care of the house….I think when they grow up they naturally…well they figure out…by themselves…what it means…We never told them why we entered the hospital and that we chose to live on the outside for a while in order for them to attend school. And how we tried not to let people know we came from the hospital. We didn’t discuss all these with our children.” Mrs. Z concluded: “They are good children. They never asked and we never talked about it.”

The community life at the same time provided motivation, materials, and occasions for story making and storytelling. By serving as each other’s audience, the community members dealt with the contradicting senses of shame, estrangement, and attachment. They told stories in which they had certain extent of connection with the outside, used to carry bacteria, and had fellows whose children did not have the disease. As a result, HD was explained by a set of scientific and lay beliefs that were weaved with individual life events.

It might seem unintelligible to embrace the identity of a patient with a stigmatizing disease. On a deeper level, it might actually be easier to embrace such an identity than to be looked down upon for being dependent on an institution. Seen from this view, the disease can be a way to deal with discredited identity.
However, it was not obvious to what extent embracing the disease was an effective strategy that helped deal with discredited identities. Explaining their stay in the hospital with their disabilities or deformities, patients came to accept the way the various outsiders saw them: that they lived in the hospital because they were not competent social members. The relationships among the patients, no matter how supportive to the patients themselves, became irrelevant in such an account.

As a result, the lingering symptoms of HD meant different things for the patients and for the outsiders. In the patient community, these meant effects of a disease patients had had and challenges they had tried to live with. To the hospital and the broader society who saw the patients through the framework provided by the hospital, the patients were unfortunate and probably pitiful individuals, a fact that could be evidenced by their having lingering symptoms of HD.

CONCLUSION
In this chapter, I analyzed the body-biography trajectories of patients before and after DDS to explain expectations and fears of stigma they still live with. I found that there were different stigmata before and after DDS. These different stigmata were shaped by medical realities of the time and were intertwined with patients’ body-biography trajectories. I also found that patients embraced the identity of an HD patient as a way to manage their discredited identity.

Before the introduction of DDS in 1954, the main issue for HD patients was to deal with their disease as a discreditable feature. Patients had to carefully manage their self-presentations in order not to reveal their disease to others. When the stigma was too difficult to manage, patients might choose to be segregated voluntarily.
After the introduction of DDS as a cure, the main issue for the patients staying in the hospital or those who had disability or deformity caused by HD (in most cases, these two situations come together) was to deal with a discredited identity. Their disease, though arrested by DDS, had already “spilled over” to other aspects of their identity. Patients had established relationships with other patients, and had relied on pension as a source of income. What they had to manage was not to prevent others from knowing about their disease, but to prevent others from looking down upon them because of the aspects of their identity stained by the disease.

Expecting and fearing stigma, patients lived with negative consequences resulting from a stigma consciousness. However, this does not mean that stigma exists only on the level of individual cognition. Rather, to the patients the stigma of HD still exists as a social reality. DDS did gradually remove the negative meanings associated with HD. But this effect was not extended to the patients I studied; they continued to live along body-biographical trajectories already shaped by HD. Actually, society’s gradual forgetting of HD’s past made it even more difficult for outsiders to understand why patients retained expectations and fears of stigma and to recognize that much had been required of patients to manage their discredited identities.

In line with recent literature on stigma (Davis 1964; Goffman 1963; Link 1987; Link et al. 1989; Link et al. 1997; Link and Phelan 2001; Rosenfield 1997; Wright, Gronfein, and Owens 2000), the stigma patients lived with comprised a persistent predicament. Segregation and stigma comprised a loop. It required a lot of patients to manage discredited identities. But the effort made for such management often drew patients back to the patient community. Moreover, the identity as an HD patient might be a convenient way to manage their discredited identity. But the price was to surrender engaging in negotiation for a less stereotyped identity. Usually what was dominant was outsiders’ view that patients were not quite competent normal social members. In
this account, patients’ efforts in search of an identity that fit their lived experiences became irrelevant.

Comparing patients’ body-biographical trajectories with Goffman’s observation of “betrayal funnel” is illuminating. Goffman found that an experience common to mental illness patients in the US in the 1950s was a gradual alienation. Progressing from home to the hospital, a mental illness patient participated as a third person in what he might come to experience as a kind of alienative coalition. In each of the stages, the patient experienced a decrease in adult free status. And patient may later realize that in the process everyone’s current comfort was sustained while his long-range welfare was being undermined. This experience contributed to patients’ feeling of separation from people on the outside (Goffman 1961).

Unlike mental patients’ experience of betrayal funnel, the patients I studied volunteered to give up relationships. This did not mean that it was easy to do so. Rather, this choice represented difficulties to eradicate stigma. Patients made much effort to manage their discredited identities, such as dealing carefully with jobs, family, medical workers, and fellow patients, and connecting in certain ways with outsiders. But still, what they did was difficult to translate into credibilities on the outside. In the end, unlike Goffman’s mental patients who have a pre-patient stage to mourn over, the patients I studied had a past that could have been different only if they were born at a different time.
CHAPTER THREE
THE BODY MECHANICAL: LIVING WITH AN IMPAIRED BODY

In Chapter Two, I have shown that, despite the effective treatment, there was a group of individuals who spent the majority of their lives in a specialized HD hospital. These individuals have been sick of a single process of peripheral neuropathy, and yet have experienced two different diseases. At the onset of their sickness, it was HD as a bacterial disease that was relevant to their diagnosis and treatment. During the process of their sickness, they found they were cured of HD as a bacterial disease, and yet continued to live with HD as a neurotic disorder. Treated by a medicine that fulfilled its promise only for future patients but not for them, the individuals became sick without a cause.

In this chapter I will show that the patients, instead of being cured, were transformed by the medicine that became able to treat HD effectively. Instead of simply bearing the physical effects of a disease, the individuals I studied live protracted in an ontological gap created by the medicine that aimed to cure them. Living protracted in this ontological gap requires much effort to deal with challenges that are at once practical and normal.

This chapter focuses on the “body mechanical,” a set of skills patients developed to keep their bodies functional. Below I introduce the theoretical underpinning of the concept of the body mechanical. Then I analyze how patients do the body mechanical. I will show that it requires patients to attend to the mechanics involved when using their bodies for conducting daily activities as well as to practice a form of self-awareness. I argue that the patients demonstrate a way of being active through embracing and coping with the state of being sick.
THE BODY MECHANICAL

To highlight patients’ effort to keep their bodies functional, I propose the concept of the “body mechanical”—a set of practices for keeping impaired bodies functional and accommodating medical treatments with everyday lives. In the same way that diabetes patients enact the body as a metabolic system (Mol and Law 2004), the patients I studied, in trying to live with bodies without sensation, enact the body as mechanics. This does not mean that the body becomes mechanical. Instead, it means finding, through trial and error, ways to coordinate the multiple elements involved in particular activities so that the body works to serve the individual. In effect, patients are concerned with what happens to their body parts when the body parts are subjected to forces or thermal energy and the subsequent effects of their body parts on their environment. They are also concerned with the payoff of particular activities. The body is constantly decaying when it is used. The goal of the body mechanical is to use the body while also trying to preserve the body for later use. Drawing on discussions of patients’ actions in the traditions of symbolic interactionism and science and technology studies, there are two theoretical underpinnings of the concept the body mechanical.

First, the body mechanical is pursuing “subjectivity through objectification”. Modern medicine experiences involve a certain extent of objectification. Modern medicine actively creates new life forms due to a discrepancy between the promise and capability of medical technologies (Timmermans and Leiter 2000; Timmermans and Buchbinder 2011), a normalization of risk (Timmermans and Leiter 2000), a tendency to objectify (Hirschauer 1991), and a pursuit of profits (Greene 2007). This multiplication of life forms is normative and can be seen as a kind of politics—the “ontological politics” (Mol 2002). For example, as modern
medicine becomes more competent to tame diseases, it promotes being effectively well as normal and suppresses dying (Timmermans 1999) and being sick (Frank 1995). Literature on illness experiences has focused on whether and how patients maintain subjectivity despite the objectification tendencies of modern medicine (Bury 1982; Carricaburu and Pierret 1995; Charmaz 1991; Kelly 1992; Kleinman 1988; Lawton 1998; Mathieson and Stam 1995; Williams 1984). More recently, there have been discussions on the extent to which patients exert subjectivity, not despite objectification, but through actively making use of objectification (Gomart 2002b; Mol 2002; Thompson 2005). Given that medicine brings alleviations as well as new forms of sufferings, this literature asks whether objectification might not be alienation (Timmermans and Almeling 2009).

This body of literature sees disease as a normal aspect of life and as transforming along with the practices they become a part of (Mol 2002). Discussing subjectivity through objectification is about how a disease is enacted—what patients do to their bodies to accommodate with their everyday life the ups and downs of disease and the multiple requirements to treat the disease. Researches have illustrated how patients enact their disease in various forms: they handle the incompatibilities between different departments of the same hospital (Mol 2002), objectify their own sexual organs to accomplish the goal of becoming pregnant (Thompson 2005), allow themselves to be addicted to a substance in the hope of breaking free from heroin (Gomart 2002b), and bear the anxiety resulting from diagnostic uncertainties (Timmermans and Buchbinder 2010). Resuscitation efforts may create the opportunity for saying goodbye to the departing loved one that is unique to the modern era (Timmermans 1999). An addictive substance may do a little more than oppressing the user—it can be a method to search for “generous constraint” (Gomart 2002b). Subjectivity through
objectification is a particular form of agency. Conducting subjectivity through objectification requires an actor to have a sense of his or her goal, and to be able to adapt.

Second, the body mechanical is about the establishment of a shared context of action. The conditions under which medicine objectifies but does not alienate are analyzable. In the same manner a serviceable technology is found to be flexible and grounded in the local context (de Laet and Mol 2000), medicine can be serviceable. Rather than pursuing life without disease or death, a serviceable medicine aims to help with living with disease (Mol 2008). Rather than being concerned mainly with equal power between health professionals and patients, in a serviceable medicine the health professionals and the patients tinker together to find out what kind of body to live (Mol 2008). Moreover, the treatment process itself is not de-contextualized but is incorporated into the daily life of the patient (Gomart 2002b). Patients seek to have multiple actors to work together. They rely on other people in their lives to provide ideas and resources when they pursue subjectivity through objectification. The connection with others in turn plays into individual patients’ identity and informs the kind of subjectivity an individual patient wants to obtain (Mol and Law 2004). The ultimate goal of patients’ active objectification of themselves may include making medical professionals have their work done. It is a kind of action that attempts to make others to conform. In this sense, it is similar to other activities such as obtaining credibility or authority. However, it does not involve the kind of strategic activities such as claim making, coalition making, or maneuvering. Instead, it involves creatively combining activities such as submission (Gomart 2002b) and adaptation (Mol and Law 2004) to attain resilience.

There are multiple but a limited set of versions of objectification. There does not need to an ultimate consensus between patients and medical workers. There just needs to be something
enduring for the duration of particular work. Thus there can be multiple versions of
objectification. However, constrained by local contexts such as the organization of hospital and
medical knowledge, there is only a limited set of versions of objectification. This kind of action,
which aims to facilitate coordination with other actors, is a kind of practical action (Garfinkel
and Sacks 1970), or articulation work (Strauss 1988). Using examples of various kinds of
infrastructure, Bowker and Star (1999) have characterized this type of action. It involves
managing multiple memberships and naturalizations in order to become part of a set of organized
practices. For the multiple, and usually heterogeneous, communities of practice to act together,
this type of action requires real-time effort to work out tensions through encoding or translations.
In line with this discussion on practical action, the concept of body mechanical focuses on the
establishment of shared context for multiple communities of practice, each with particular
working orders. A set of practices that is rational in one realm of medicine (such as pathology)
might not be so in another (such as clinical medicine). And a set of practices that is rational in
one realm of medicine might not work in patients’ daily lives. The concept of the body
mechanical explores what patients do to their bodies to allow various realms of medicine and
their everyday lives to work together.

In sum, the body mechanical is to find a local context in which heterogeneous actors
work together with the goal that the body could work. It sees disease as a normal aspect of life.
And it tries to be flexible in the local situation. The concept of the body mechanical emphasizes
actual practices taking place in the real scenes of medicine, and the consequences of those
practices. It explores what patients actually do to their bodies and what becomes of their bodies.
Below I will show that patients try to have a sense of his or her goal, to be able to adapt, and
sometimes take risks. The purpose is not to come up with detection and treatment of
abnormalities. Instead, the purpose is to have a configuration of body-environment, so patients can go about activities such as cooking, going to church, grocery shopping, and attending a tea table.

The analysis of this chapter is composed of two parts. In the first section, I analyze the scope of the body mechanical, showing that it seeks to address a condition between sickness and health. In the second part, I analyze what patients do to make the impaired bodies function, and how they cope when the life world and the medical world are in tension. Enacting a “body mechanical”—a set of practices that require constant adapting and improvising efforts, patients strive, though sometimes also fail, to establish a context of action shared with relevant others and medical workers.

THE SCOPE OF THE BODY MECHANICAL: NEUROPATHY AND NEUROPATHIC ULCERS

At around 2 o’clock in the afternoon, Mrs. Y made an appointment to meet with a surgeon. As she was walking from the counter towards the treatment room, she saw the surgeon coming.

Mrs. Y said to the surgeon: “Dr. W, my big toe is bothering me again.”

Dr. W: “Are you taking any medications for that now?”

Mrs. Y: “No. You will give me antibiotics for that, right?”

Dr. W: “Well, it’s not always necessary.”

Mrs. Y entered the treatment room, sat down on a bench, and put her left foot on a stool. She said to Dr. W: “It hurts a little bit. Sometimes it’s better. Sometimes it gets worse.”

What Mrs. Y had was a “neuropathic foot”—a foot that had no protective sensation. She had limited awareness of foot injuries. The wound she had on the big toe was a “neuropathic
ulcer.” Mrs. Y had two neuropathic ulcers to take care of—one on her big toe, and the other on her lower calf. She had had both of the ulcers for a long time. Neuropathy, including sensation loss and paralysis, is common among the residents of the hospital. Sensation loss can happen in the ulnar half of the hand, the lateral half of the hand, the index finger, the lateral side of the leg, the dorsum of the foot, and the sole of the foot. Paralysis can happen in the fingers, the wrist, the foot, and the toes. Together these conditions can lead to clawed hands, dropped wrists, clawed toes, collapsed arches, and dropped feet.

In medical textbooks, “neuropathy” and “neuropathic ulcers” appear as two things. “Neuropathy” is a phenomenon of a bona-fide disease, while “neuropathic ulcers” are an unfortunate effect of a disease that simply needs to be lived with. Take this discussion, for instance, from a 1985 medical textbook: “Treatment of the leprosy itself often leads to some recovery of sensation and that lost during a reactive episode may be partially or fully recovered with treatment of the reaction, but most sensory loss is permanent. Thus the patient must learn how to live with it and avoid injuring the insensitive areas” (Jacobson 1985: 217; emphasis added). Following this distinction between a bona-fide disease that can be tamed by treatment and an unfortunate effect, the “Rehabilitation in leprosy” section of the same textbook distinguishes between primary and secondary deformities in HD. “The disease of leprosy is not itself directly responsible for most of the deformities that are attributed to it,” it notes. “It characteristically removes the sensation of pain, and so allows the patient to damage himself. The more closely one studies the natural history of deformity in leprosy, the more one finds that secondary and sometimes almost incidental damage and infection have been the cause of most of the mutilations from which these patients suffer” (Brand and Fritschi 1985: 287).
However, when patients and doctors attempt to prevent HD from interrupting lives, there is only one HD, rather than two (neuropathy and neuropathic ulcers). For example, if one refrains from all the activities and as such avoids getting ulcers, neuropathy would not be a problem. In the afternoon when Mrs. Y went to see Dr. W for the wound on her big toe, Dr. W advised Mrs. Y: “If you don’t walk, the wound will heal.”

Ulcers are not just inseparable from neuropathy. Actually, it is usually the ulcers that come before the neuropathy. Ulcers are in effect a sign that makes one realize that he has lost sensation, and, as such, what motivate him to see a doctor. When asked to describe their experiences of HD, residents usually identified loss of sensation, paralysis, and ulcers as the causes that urged them to seek medical attention. Mrs. Y, for example, described her earliest experiences of HD: “I went home after school and was cooking. I touched the pan and burnt my hand. See how stupid was I! I didn’t notice the burn. My sister noticed it and wrapped the wound for me. She didn’t know how to do it correctly and tied these two fingers together. I also broke bowls many times. My stepmother hit me on the hand. So this finger [pointing at the ring finger of the right hand] is a bit bent.”

Through challenges of conducting daily activities, patients experience what in medicine is “neuropathy”, in the form of inadvertently hurting themselves and developing what are known as “neuropathic ulcers” in the medical literature. It is thus these neuropathic ulcers and other disabilities that constitute illness experiences, rather than neuropathy itself.

The way in which HD is treated also reveals the extent to which disabilities and ulcers, instead of neuropathy, are central to how patients and medical workers actually deal with HD. Treatments for HD are aimed at preventing neuropathy. However, if disabilities or ulcers are absent, then there is no way for a doctor to determine whether a patient’s condition has
improved. One patient had received DDS treatment since childhood. The disease attacked her again after she gave birth to her first child. When asked whether her disease had improved after she first received DDS treatment as a child, she answered in a way that emphasized the centrality of wounds. As she put it: “How do I know whether I was better since it did not attack me? I was the same whether I took it or not. The disease attacked me after I got married and gave birth to my son. [Pointing to her arms] All these scars are from that time. Many on my feet too. All over my body.”

In the logic of medicine, an HD patient has neuropathic ulcers because of neuropathy, which in turn was the result of Mycobacteria leprae (M. leprae) infection. In real life, however, neuropathic ulcers and neuropathy are inseparable. It is the disabilities and wounds that urge a sick person to seek medical attention. It is also these disabilities and wounds that mark out to the patients the distinction between sick and normal. Since they are still bothered by injuries that frequently turn into ulcers, patients consider themselves to still be sick of the disease that is called HD.

**THE WORKING ORDER OF THE BODY MECHANICAL**

Living with neuropathic hands and feet means having to consciously find ways to keep the body functional. It is important for the residents to always carry out evaluations of their different body parts, assessing the mechanical force and thermal energy involved in a given activity. I identify four strategies that help keep one’s body in working order: to prioritize, to excorporate, to incorporate, and to reconfigure. First, patients want to preserve their hands and feet. But they also want to use their hands and feet rather than simply devoting all their effort to preserving hands and feet through inactivity. Therefore, they need to prioritize the multiple imperatives for
conducting everyday activities and for preserving their body parts. Second, they “excorporate” (Mol and Law 2004)—they arrange their environment in a way that allows their body to work. Although neuropathy is restricted to the hands and feet, the whole body is involved in body mechanics. Having no sensation means a vital link in the chain of self-preservation is missing. This kind of self-preservation depends in no way on intelligence or forethought. Instead, it depends on bodily senses—the sense of pain and the early warnings of pressure and temperature. Having no sensation, patients need to shape their environment to fit the ways their bodies work. Third, they incorporate—allowing other actors to be part of their body mechanics. Finally, if the overall configuration of the elements involved in their body mechanics turns out to be too burdensome, they need to give up some of the elements, thereby reconfiguring their body mechanics.

It is important for a patient in a hospital to use the mechanics of his body to assess what is most important to him. In the same way drug users use methadone to achieve the possibility of turning away from heroin (Gomart 2002b), and diabetics use a portable machine for measuring their blood-sugar levels to train themselves to feel the onset of hypoglycemia (Mol and Law 2004), HD patients use the mechanics of the body to coax themselves into practicing self-awareness.

I. Prioritizing

Bodies can be understood in relation to mechanical forces, such as heat and pressure. When patients do so, the effects of their activities on body parts are more or less predictable. Some generalized rules are suggested to the residents: never walk without footwear, shoes must always be shaken out before they are put on; think more about the area of application of force than about
the amount of force; remember that one can never be quite sure that a pot or pan near the stove is not hot; never wear new shoes for more than two or three hours at a time for the first day or two; make frequent visual inspections of hands and feet to see whether they are wounded.

However, understanding the body in relation to mechanical forces is not equal to knowing how to live. Patients have to assess the trade-offs between an activity and the risks it might bring to the body. Take Mrs. Y, who visited the physician for her big toe. Just as the physician did, we can predict that the ulcer on her big toe would heal if she stopped walking. Mrs. Y certainly wants the ulcer to heal so that she can wear her favorite shoes and go to church on Sundays. However, during the period of time when she refrains from using her feet, she cannot go to church in her favorite shoes, and, if she cannot do this, taking care of the toe has lost its meaning. Considering her age and that each day counts, it is not so obvious that she would want to refrain from using her feet. It is thus a question of deciding how important wearing her favorite shoes to church is and whether she is willing to live a period of time without this activity. In the treatment room that afternoon, Mrs. Y decided that Dr. W’s advice was absurd. After Dr. W left the room, Mrs. Y said to the patient sitting next to her: “How is it possible not to walk?”

Cooking also illustrates the importance of prioritizing. Fingers without sensation might be burnt during cooking. As a person who likes cooking, Mrs. Y faces a choice: to live with intact fingers that nonetheless are not functioning in a way that serves her, or to cook for herself and risk burns. Her decision is that cooking is important to her as a daily activity, but not as important as her occupation. In the past, she had tried to make a life “on the outside” by moving to another city and finding a job as a cook. She burnt a few fingers during the job. After deciding that the life as a cook was not for her, she returned to the hospital. This was not something she
knew beforehand. It was something she learned while doing things she wanted to do. In attempting to come to terms with their neuropathic bodies, patients are constantly trying to answer one question—what kind of person am I?

Mr. K had the lower portion of his right leg amputated a few years ago and later started to wear a prosthesis. After waking up each morning, Mr. K immediately put on his prosthesis. He did not take it off until he went to bed. Knowing that some patients in the hospital had undergone a second amputation because of wounds taking place on the surface of leg that touched the prosthesis, I asked him whether physicians ever told him to walk less often. Standing in his garden with a water hose in hands, he said: “To walk less often? These flowers would die very soon in this kind of weather!” It was not that Mr. K was unaware of the likelihood of a second amputation. It was that keeping his way of life was to him a better way of living. In his way of life, Mr. K watered his vegetables and flowers every day, and twice a day in the summertime. He gave the vegetables and flowers as gifts to his friends. Occasionally he earned money from selling them. In addition, Mr. K and his friends enjoyed sitting next to the garden and having tea every day.

II. Excorporating

The patients also excorporate—they shape the spatial and temporal orders of their immediate environment to fit the ways their bodies work. Patients sometimes do so by inventing innovative ways of connecting with their environments. Mrs. Z’s right hand was clawed, but because she was right-handed, she still used her right hand for many activities, such as holding a knife, a needle, or a pen. She only used her left hand for difficult activities, such as scratching and buttoning. However, having a clawed hand, especially in the hand she used the most, did not
restrict Mrs. Z. She had organized her environments in a way that her hands were good enough to conduct the activities important to her. Demonstrating how she sewed, Mrs. Z held a needle in the cleft between her index finger and thumb of her clawed hand, and said: “I can hold a needle even like this.” She was also creative when chopping. She used her left hand to steady the object she will chop, and used her right hand to hold the knife, again in the cleft. She said: “This is even better”—she meant having a clawed right hand was better than having a clawed left hand. By acknowledging her clawed hand, and by creatively rearranging the ways she conducted daily activities, Mrs. Z made her otherwise impaired body function for her.

Excorporating sometimes involves rearranging the environment collectively. Maintaining a tea table, for example, requires such collective effort. At the tea table next to Mr. K’s garden, tea was provided throughout the whole day. Any community member who happened to stop by could casually have a cup of tea and chat for a short while.

At a quarter after 3 pm, Mr. C arrived at Mr. K’s tea table. As usual, Mr. K was already at his garden-side table drinking some tea. Mr. C rode his electric scooter forwards and backwards several times, parking it right next to the table. The same scooter that was a tool for transportation was now Mr. C’s chair. A few minutes later T, a nursing assistant from Indonesia whom Mr. C hired, and who was on foot, would arrive too.

Mr. K: [referring to the snacks on the table] “Which of the snacks do you want?”

Mr. C: “No, I’m fine.”

Mr. K: “Or you want to wait for T [the nursing assistant employed by C] to help you? How about coconut cookies?”

Mr. C: “I’ll wait for T.”
To maintain a tea table in the hospital required patients to shape the spatial and temporal orders of their environment in a very particular way. The table needed to be set at a location that was tended to regularly by fellow patients. This way it was convenient for the patients to casually stop by. And fellow patients’ constant tending made the place felt communal. This arrangement of location was important to patients in the hospital, many of whom had disabled feet. Moreover, tea needed to be served throughout the day, so that a casual stop-by could also be a chatting over tea. Hence there had to be a patient living by the location whose hands functioned well enough to make tea. While in other communities, having tea at a tea table could be a flexible activity, in the hospital only where these factors came together did a tea table exist.

Mr. K’s tea table was arranged to fit patients’ body mechanics. At the same time, it socialized patients in practicing body mechanics. That Mr. K invited Mr. C to have snacks was a provocative action. Both Mr. K and Mr. C had two clawed hands. For both of them, it was not possible to carry out tasks that required delicate manual actions, such as opening a package of cookies. Knowing Mr. C’s restriction, Mr. K still invited Mr. C to have a snack. Knowing Mr. K’s restriction, Mr. C did not take the invitation as empty or offensive. He simply observed the courtesies between a host and a guest by saying that he was fine for the moment and he would wait for his nursing assistant. At the table, the invitation and the response were buttressed by the mutual understanding that helped maintain otherwise impossible courtesies. By making the effort to maintain such courtesies, Mr. K and Mr. C allowed the tea table to continue to be a tea table. The maintenance of the tea table was pleasurable and, importantly, provided a place for patients to neutralize disabilities and to socialize into practicing body mechanics.

III. Incorporating

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The patients also incorporate—they let other actors, including other patients, medical workers, and certain outsiders become part of their body mechanics. Incorporating other patients helps one’s body mechanics run smoothly. A while after breakfast, Mrs. Y was taking a shower in the bathroom. The four women with whom Mrs. Y shared the room were in their respective beds. A slight buzzing sound and then a person in a three-wheeled electric scooter entered the room. One of the four women in the room mumbled: “Who is that? Oh, it’s S.” Mrs. S drove her scooter forwards and backwards several times to reverse its direction and to park it in the aisle between the beds. On the handle of the scooter were hung several plastic bags she had brought back from the market. After Mrs. Y came out of the bathroom, Mrs. S said to her: “I want to ask you. They didn’t have wahoo. Is swordfish fine? I was thinking if you don’t want it I’d keep it for myself.” Mrs. Y replied: “Swordfish is good too. It’s good enough to have someone shop for me.” Mrs. Y found her money and gave it to Mrs. S.

During this ordinary scene of a friend stopping by on her way home, some other things also happened: a fish and money were exchanged. This simple event, in fact, said a lot about the lives of the residents. Mrs. Y’s ulcers needed to have their dressing changed every day. If she went to the market she would miss the nurse, who would stop by at about 10am for changing her dressings. Mrs. S knew Mrs. Y well and offered to shop for her. She looked for things Mrs. Y might want while she was doing her own shopping. If Mrs. Y did not want what she brought back, she would keep it for herself. During this short visit, both the visitor and the visited found chances to care for each other.

Incorporating doctors and nurses also facilitated body mechanics. Patients incorporated doctors and nurses by urging them to bring together patients’ life world and their work. Such incorporation allowed patients to get more medical attention, and helped tailor the care they
received to their needs. When a physical therapist, during a therapy session, heard Mrs. Y mention falling down in the bathroom, he called his coworker to arrange for an X-ray examination. If he had not been familiar with Mrs. Y and developed the habit of chatting with her, then the examination might have had to wait until the following day, after Mrs. Y had made an appointment. The nurse working in the room for changing dressings made phone calls to Mr. K so that he could come have his dressings changed. In this way he did not have to spend his time waiting in line. Instead, he could use his time to join the tea table. For the nurse, doing so had the effect of motivating Mr. K to change his dressings earlier in the morning rather than to wait until noon. The nurse could thus finish her work earlier. In another example, a nurse discovered that a patient was constantly getting burned. The patient was not willing to explain why. Yet, from the patient’s neighbor, she knew that the patient insisted on cooking. Knowing this detail about the patient, the nurse tirelessly reminded the patient to be careful with hot pots. Details like these also helped the head nurse arrange for nursing assistants to help with activities like cooking and showering.

People who, like the residents, needed alibi for certain aspects of their social identities became relevant outsiders of the community: foreign spouses, nursing assistants, children of residents who did not have decent jobs on the outside, and prostitutes. Many of these were women and had more than one of these identities. A foreign spouse or a child could become a nursing assistant hired by the hospital or by the patients. A prostitute could become a wife and did many of the jobs that a nursing assistant did. Mrs. N was such an outsider-turned community member. She had lived in the hospital for almost 30 years. She was first introduced to the hospital by a customer whom she later knew to be an HD patient when she was working at a casino. Mrs. N later got married with a patient. She said: “He is such a good guy. I told him I had
no money for furniture. He gave me his account and told me to use as much as I needed. I withdrew ten thousand and I told him. He said that’s OK, as long as you don’t cheat on me. How can I cheat a guy like this.” Commenting on her becoming a community member, she also said: “I just want a family.”

IV. Reconfiguring

Patients reconfigure the working order of their body mechanics when a variety of challenges appear. First, it might become apparent that it requires too much to keep a foot, and that amputation is the lone option. Second, because the whole body is involved in one’s body mechanics, losing one’s sight or falling down can have serious consequences. Third, other patients who are part of one’s body mechanics may die and medical workers may leave for other jobs. In each of these situations, the patients need to reconfigure their body mechanics in hopes of eventually attaining a new balance.

A. Amputation

Despite a patient’s best effort to care for his hands and feet, there is no guarantee that they will continue to function as long as the individual lives. Unforeseeable negligence sometimes takes place. New injuries happen. Mrs. R normally asked the nurse to cut her nails for her because she was unable to use a nail cutter effectively. Once, the nurse accidentally made a small cut in Mrs. R’s finger, and the cut became inflamed.

As well, deformed limbs tend to become inflamed. One of Mrs. G’s feet was deformed from over-supination. Supination is a normal feature of one’s gait that allows the foot to form a rigid structure for propulsion. However, because of HD, Mrs. G was not able to control her foot and it was always supinated. Accordingly, when she stood, most of her weight was placed on the
outer edge of her foot. The long-term strain caused by over-supination constantly caused inflammation. Whenever her foot was inflamed, Mrs. G needed to take a break from her work and took medications.

Like in the above examples, patients sometimes discovered that, in the end, the work required to preserve a foot exceeded the value of the foot itself, and that it might be better to give up the foot. This was not an easy conclusion to draw. Mrs. G came to this conclusion after being hampered by over-supination for about twenty years. She made up her mind to amputate the foot when she was 36. Mrs. G said: “He [the doctor] told me that way it would be easier for me to walk. He’s right. It worked until recently.” Mrs. G received an amputation again in 1999, when she was 55, because a wound developed on the scar resulting from the first amputation. For an outsider, it sounds paradoxical that Mrs. G was satisfied by a medical procedure that did not allow her to keep her own foot.\(^2\) It is less paradoxical when the efforts it requires of patients to keep a foot are taken into consideration. Actually, sometimes it is one’s life that is at stake. Mrs. D was such an example. Her original injury started as a small cut but worsened rapidly because of the diabetes she acquired in old age. Within a few days the doctor decided that amputation was necessary to prevent the wound from endangering her life. Mrs. D said: “He said he promised to cure me. So he cut to here [pointing to her thigh]. He’s right. I haven’t had injuries since then.” Another patient commented on the amputations: “It’s true that the foot is yours. But if it’s not for you to use, you don’t have a choice.”

An amputation, though, is not an end to the body. Instead it is a first step in rebuilding the body’s working order. After lying in bed for a few days, Mr. W, who had his left foot amputated, started to receive physical therapy. He received massages and learned to massage the muscles near the amputation so that his muscles did not harden. Bandages were applied every day to
ensure that the muscles would be suitable for a prosthesis. Mr. W also learned to do exercises that focused on the muscles near the amputation. Then a contracted prosthetist came to make measures in order to make the prosthesis. After a patient receives a prosthesis and learns to walk with it, he continues with the challenge that he has already been living with—the challenge of taking care of oneself. He learns to wash himself again, and to prepare and have his meals. In time, these play into his personal routines and the routines of the community.

B. Diseases or Malfunctioning in Other Body Parts

What is required to take care of a neuropathic foot may be in tension with what is required to take care of other parts of the body. For a wound to heal, it is important to refrain from using the body part that is injured, such as a foot. But if one does not walk, his leg may become weaker. And this increases the possibility of falling, which can make things difficult. One patient fell when she was trying to move a table in her room. She lay in bed for a few days after falling. When she felt well enough to walk, she discovered that her thigh had become slightly fatter and that her prosthesis no longer fitted.

Losing sight is especially difficult for patients because they rely on their eyes for monitoring their movements. But to avoid sight loss is itself a demanding task for one whose fingers are not functioning. Mr. K, who insisted on working in the garden even after his amputation, had not worried about the possibility of a second amputation. But sight loss was something that made him anxious. Having no sensations, Mr. K relied totally on his sight to gear his movements. If he lost his sight, he would be, in his own words, in total darkness. To prevent the possibility of losing his sight, Mr. K used a cataract eye drop every day. This added to the list of activities for which he relied on others. He relied on a hospital nursing assistant to squeeze the liquid drops into his eyes. This in turn made Mr. K to start worrying about money. Fearing the
possible days in darkness, he became aware of the need to hire a personal nursing assistant who would be available even during the hours when the hospital nursing assistants were off.

Diabetes also poses a risk. The incidence of diabetes is independent of HD. Nevertheless, patients develop diabetes, and the condition increases the odds of ulcerations.

C. Change in Personnel

Because body mechanics rely in part on other actors, when money is used up, or a nursing assistant changes jobs, the order of body mechanics also needs to be reconfigured. Family members might be able and willing to care out of duties or obligations, but they were just not available a lot of the time. An outsider-turned partner was caring. But the relationship was not necessarily stable. Patients relied a lot on the hospital in these situations. However, the hospital nursing assistants were not available during nights and weekends and so it was often useful to have a personal nursing assistant. And yet, having lived in the hospital for most of their lives, many of the patients had a limited amount of money. Moreover, personal nursing assistants changed their jobs frequently and it was not easy to find new matches. Changes in personnel pose a particular challenge for patients.

Mr. W was one who used to live with a “foreign spouse” from mainland China. This outsider-turned partner originally came to the hospital as another patient’s wife. Mr. W had known her because he hired her to wash his clothes. Mr. W started to live with her after her husband passed away. Mr. W said: “I found her pitiful and a staff suggested to me that it would help her if I live with her. That way she is justified to live in the hospital.” After hearing about Mr. W’s version of their story, Mrs. Z laughed and said: “That’s not true. People started to say that the two would be together even before the husband died.”
Mr. W’s life with a partner did not last long. The partner returned to mainland China after living with him for a couple of months. Mr. W said: “She did not ask me to visit her. She knew that was impossible for me. She just told me to take care”. He also said: “I still shed tears thinking of her now.” After the partner left, Mr. W had no one to wash his clothes, cook for him, and help him take a shower. Things became even more difficult after he had an amputation. He thus asked the nursing assistant hired by Mr. C to come to help him with showers. The nursing assistant came on Monday, Wednesday, and Friday after she sent Mr. C for receiving dialysis. Mr. W would pay the nursing assistant each time she came.

Most of the time, Mr. C was confined to his bed. Since he became bed-ridden, he had stopped using his prosthesis and hired a personal nursing assistant. After working for Mr. C for two years, the nursing assistant, a foreign worker, returned to her own country. Mr. C hesitated in hiring a new assistant. His savings were enough for him to hire a nursing assistant for only three more years. He started to consider walking on his prosthesis so that he might not need to hire someone too soon.

Commenting on the money issue, Mrs. M, who was a leader in the community, said: “people die when the money is used up.” Knowing how difficult things might be in such situations, she jumped in for those who were seriously ill and had no money. She visited them, cooked for them, and arranged for them to share nursing assistants.

CONCLUSION: DOING THE BODY MECHANICAL

As embodied beings, we all practice a kind of body mechanics. The HD patients I studied, however, practice a “body mechanical.” They learn to be aware of the possible consequences of using the body in particular ways and to do only what is really important to their lives. It helps to
prioritize, to excorporate, to incorporate, and to reconfigure one’s body. Practicing the body mechanical means to use the body and, while using the body, to decide what becomes of oneself.

It is not easy to manage simultaneously all the imperatives of the body mechanical. The goal is to use the hands and the feet until the end of life and, while living, to wear a favorite pair of shoes to church, to cook, sew, or join a tea table. Help is always good, and help from medical workers and fellow patients is no less important than help from children, outsider-turned partners, or nursing assistants. However, there are a lot of challenges. Patients do not want their children to become a part of the patient community. Relationships with outsider-turned partners can be unstable. And nursing assistants can be expensive. New injuries and other diseases happen. If the goal of using the hands and the feet until the end of life proves impossible, then the patient needs to adjust his or her circumstances again, by amputating a foot, for instance, or by giving up a cherished activity.

It is surprising how flexible patients are and how they are able to function until the end. Mrs. R had been nearly bed-ridden for several years. Her upset stomach had made her even weaker. However, when she heard that a close friend had been diagnosed with lung cancer, she pushed herself to move outside her room on a chair, and went to her friend’s room. Previously, Mrs. R had stayed in her room most of the time and moved around in the room on a chair. It was not easy for her to go to other rooms or other floors without the help of others who could move her in a wheelchair. Sitting next to her friend’s bed, with the television on as a background noise, Mrs. R asked her friend what she was going to eat for dinner and listened to her complaints about her pains. She told the friend: “That’s just the way it is. We were born with our bodies.”
Endnotes

1. For a marvelous ethnography documenting a coffee table that facilitates interracial respectability in a group of American black and white men gathering over drinks and foods, see Duneier 1992.

2. For a discussion on the paradox about amputation in the case of atherosclerosis, see Mol and Elsman 1996.
CHAPTER FOUR
SLIT SKIN SMEARS AS A RATIONALIZING TOOL

Technician: I feel that we’re just doing role playing.

YH: For whom to see?

Technician: [shrugged] I don’t know.

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Technician A: Actually we don’t need to make the smear. It will be negative.

Technician B: You need to do it so you can say it’s negative.

(Conversation during breaks from giving SSS examinations in 2011)

FORMAL AND SUBSTANTIVE RATIONALITIES

Technicians working in the HD hospital today still give SSS examinations to both residents of the hospital and outpatients. When giving the examinations, they feel an anachronism in multiple ways. First of all, because the patients have had negative examination results for several decades, giving the examinations makes no difference in terms of treating individual patients. And since the disease has been eradicated from Taiwan, giving the examinations is not necessary in terms of disease prevention. In some other countries, there have been cases of relapse (World Health Organization, Regional Office for South-East Asia 2009). But in Taiwan there have been few cases. At the same time, however, SSS is a tool that provides rationality for the HD hospital as a center of a health program aimed at prevention—it produces examination results that mark conformity between the objective of HD hospital as a part of a disease prevention program and
the belief in scientific evidence. But still, the ambivalence is there: does the slight possibility of relapse justify the continuation of the prevention program? Why does medicine actively institutionalize the sick role?

In the previous three chapters, I have shown that DDS facilitated an HD prevention program focusing on treating the pathogen of HD. Under the new treatment regime, a part of patients found their body-biography trajectories developed around HD. Moreover, their illness experiences were characterized by objectification of their bodies. In this final substantive chapter, I will show how the same set of medical practices that aimed to cure patients made patients’ experiences irrelevant. I do so by following a rationalizing tool in the HD prevention program—the SSS examination. I argue that the use of SSS serves more to obscure rather than to reveal the lived experiences of patients.

To explain the paradoxical use of SSS, I draw on Stinchcombe’s (1986) conceptualization of rationalization. Stinchcombe made a distinction between formal rationality—standardized methods of calculation on which routines can be based—and substantive rationality, which goes behind formal methods to the substance of the matter. The importance of making the distinction and exploring the relationship of the two lies in that, for reliable social organizations of calculation to be viable, there needs to be routines and procedures that can be judged quickly by external features and can be conducted by ordinary individuals. However, formal rationality is only as good as its grounding in substantive rationality. In different contexts, there are different ways of organizing the routines and procedures so that they are grounded in substantive rationality. Using mass production industries and construction industries as examples, Stinchcombe (1959) explained how different industries decide the most efficient way to pursue rationality. In mass production, bureaucracy is an efficient way for
rational administration. Both the product and the work process are planned in advance by persons not on the work crew. Bureaucracy enables communications on the basis of files and the economical employment of clerical workers. In constructions, professionalization is more efficient. This is because bureaucratization relies on stability, and yet construction is featured by economic instability. The work in constructions thus requires administrators to adapt to variability in volume and product mix.

Recent literature in science studies contains multiple insights to refine Stinchcombe’s conceptualization of rationalities. First, there can be multiple substantive rationalities (Berg 1997). What eventually becomes the defining substantive rationality for an institution might be just one among the multiple substantive rationalities. Studies in medical history suggest several sources of substantive rationalities. Substantive rationalities can come from the attitudes and aspirations that gave the profession its peculiar identity (Rosenberg 1995). Rosenberg observed that in the late 19th-century America, there was a gradual acceptance of the technical superiority of special practice. By the 1880s, it was generally understood by both laymen and physicians that the highest quality of care and competent teaching could only be guaranteed by men “such as have attained more than ordinary proficiency in one or more of the special departments of medicine.” Substantive rationalities can also come from the ways in which medical science understands diseases. Twentieth-century US investigators, clinicians, and patients have employed only a limited number of explanatory strategies for reconciling tensions between two ideal-typical visions of illness—individual sickness and specific disease. These strategies include recasting of holistic approaches to individual predisposition in moncausal, individualist terms, medicalization of idiosyncrasy, emphasis on patient-centered definitions, and the idea of risk factors (Aronowitz 1998).
A second insight from science studies is that, formal and substantive rationalities are usually intertwined. There is no smooth fit between medical work and medical tools. Rather, specific tools and practices shape each other in the process of adopting a tool (Berg 1997). Tools translate the job in order to work (Akrich 1992; Clarke and Fujimura 1992). This transformation may be constructive for the actors involved (Gomart 2002b; Mol and Law 2004). But it can also involve high prices such as living protractedly between sickness and health (Greene 2007; Timmermans and Buchbinder 2010). Under this view, what Stinchcombe sees as a formal rationality that is grounded in substantive rationality might be productively reframed as a mutual construction between formal rationality and substantive rationality.

Building on Stinchcombe’s conceptualization of rationality and science studies’ insights, I come up with the idea of “bureaucratic normalization.” This idea emphasizes the context in which a particular substantive rationality becomes what defines the job for an institution. It also emphasizes how tools and practices emerge together during the process. The adoption of SSS as a rationalizing tool for the HD prevention program illustrates these features of bureaucratic normalization. The HD prevention program aimed to rationalize HD medical work so that the cure for HD (i.e. DDS) could be delivered by a few medical workers to patients who were scattered across Taiwan. The rationalization of medical work for the HD prevention program did improve the overall effectiveness of the program. But at the same time, the rationalization emphasized HD as a specific disease. It defined the pathogen as the authentic disease that required intervention. As such, the same rationality that led to the overall effectiveness of the program facilitated a medical framework as well as a set of practices in which patients’ experiences became invisible.
To work out this argument, below I follow the process of adopting SSS by the HD prevention program. In the first part, I show that in the context of limited funding and personnel and the emphasis on pathogen as the disease, delivering the cure to as many cases as possible became the goal. In the second part I analyze how the work in the HD prevention program was reorganized to fit what SSS could do. I will show that the work became bureaucratized. In the third part I analyze the current use of SSS. I will show that there has not been a perfect fit between the work and SSS. The continual execution of SSS examinations filled in the rupture by providing a convenient justification of the prolonged institution of cured patients. Through the analysis, I will emphasize that the rationalization of HD prevention program simultaneously, and paradoxically, improved the overall effectiveness of the medical work and made experiences of a part of patients irrelevant.

SSS AS A RATIONALIZING TOOL

In this section, I illustrate the context in which SSS became a rationalizing tool for the HD prevention program in Taiwan. When DDS was introduced in 1952, physicians became confident that HD can be cured. To use DDS to eradicate HD, however, depended on the covering and monitoring of cases. Because patients were scattered and there were only a limited number of medical workers, the covering and monitoring of cases had to be manageable. SSS made the work rationalized and thus manageable by a small group of medical workers. Below I start by talking about a standardized version of SSS adopted along with DDS. Then I illustrate the role of SSS in the mass treatment approach of the HD prevention program.

I. A Standardized SSS
Physicians in the early 20th century had been trying to find bacteria from patients’ lesions as a method to confirm diagnosis (Aoki 1927). But it was in mid-century that SSS became standardized. In 1952, the young Dr. Chau Rong-fa was selected to learn the DDS treatment for HD at the Hei Ling Chau leprosarium in Hong Kong. The Hei Ling Chau leprosarium was staffed by a British physician who was then deemed as an authoritative figure in the field of HD. After a year, Dr. Chau returned to Taiwan and worked at the HD hospital in Taiwan. He brought back with him knowledge of diagnosis and treatment as well as a standardized version of SSS (Liang et al. 2008). This version of SSS made smears from six parts of the face (Losheng Sanatorium 1955). It made HD describable in terms of the density of bacteria in the body of patients. When observing the smear under the microscope, the medical technicians would count the amount of bacteria within each field. According to the amount of bacteria within each field, the technician would assign a BI ranging from 0 to 6 to each of the six smears.

The result of SSS was an important criterion for evaluating the improvement for individual patients. By making HD describable in terms of bacteria, SSS provided an orientation for treatment. A relationship between symptoms and bacteria load was established. Physicians before SSS had been able to distinguish between the lepromatous type of HD and the tuberculoid type of HD based on the symptoms. The lepromatous type of HD is characterized by symmetric skin lesions, nodules, plaques, thickened dermis, and frequent involvement of the nasal mucosa resulting in nasal congestion and nose bleeds. The tuberculoid type is characterized by one or more hypopigmented skin macules and anesthetic patches, where skin sensations are lost (Aoki 1927; Hastings 1985). After the introduction of DDS, the lepromatous type started to be equated with multi-bacillus and the tuberculoid type with pauci-bacillus. Overall, the dose for the lepromatous type was higher than the tuberculoid type. However, for the type of patients who
had a high density of bacteria (the lepromatous type), the use of DDS had to start from very low
doses and be gradually increased to the regular doses to avoid triggering lepromatous reactions.
DDS could be stopped when the SSS result became negative. For the types of patients whose had
a low density of bacteria (the tuberculoid type), DDS could be stopped after the symptoms
stopped progressing (Losheng Sanatorium1955).

SSS also provided a way for deciding whether a patient needed being hospitalized and
whether he or she could be discharged. At the time when a patient was seen for the first time,
SSS was given to see whether the patient was infectious. If the patient was infectious, he or she
would be hospitalized. In the hospital, the patients received SSS twice each year. For patients
whose SSS results were already negative, SSS was given every 1-3 months to make sure that
they could be discharged. If the patient had three or four negative result for three times
consecutively, the patient could be discharged (Losheng Sanatorium 1955).

II. The Mass Treatment Programme

The standardized SSS was central to the HD prevention program, which was based on the idea of
mass treatment. The idea of mass treatment came from the World Health Organization (WHO)
expert committee of leprosy. Mass treatment was the term applied to the treatment of a large
number of patients with standardized methods by paramedical personnel under the supervision of
doctors. A mass campaign consisted of a case-finding programme pursued on a large scale in
highly endemic areas combined with treatment of detected cases by standardized methods. In this
work, paramedical personnel could be utilized under the supervision of doctors. The Committee
emphasized that wherever a campaign was to be undertaken it was essential to establish a central
leprosy service. The head of this service should be a leprologist with knowledge of public health
administration who should be appointed to the senior grade in the health service of the country (World Health Organization 1960).

The Committee recognized that there were three phases in the development of HD campaign: attack phase, consolidation phase, and integration phase. The HD campaign should begin with case-finding and treatment. Case-finding would become more successful as the efficacy of sulfone treatment was recognized by the public. It was carried out by mass examination of the whole population, house-to-house case finding, contact tracing, or examination of previously selected groups of the population, depending on the level of prevalence. The consolidation phase followed the preceding one immediately when the ceiling of case-finding had been attained. HD was a chronic disease, and patients had to be treated for years. Case-holding was the most important part of the consolidation phase. Means of ensuring the regular treatment of registered cases included mobile circuits, e.g., by automobile, bicycle or other means of transport, and out-patient clinics. In the integration phase, the treatment of HD patients should be part of the general health system. At the beginning case-finding and re-surveys should be carried out by the specialized HD personnel, but when integration was complete these functions should be assumed by the general health services, working from health centers (World Health Organization 1960).

Starting from 1953, the medical examination lab of the HD hospital in Taiwan began the work of establishing SSS records for each of the patients living in the hospital. Dr. Chao, who was a central figure in this work, saw as the objective of the work to gradually replace institutionalization with outpatient clinics. He estimated that there were 7000 patients in Taiwan, 2000 among whom were infectious. He also estimated that the HD hospital was able to accommodate up to 1000 of the infectious patients. With the establishment of two other locations
for accommodating infectious patients, the infectious cases could be segregated. The rest of the patients would receive treatments at home. To reach this goal, it was important to discharge existing cases that were noninfectious to allow accommodation of new cases (Losheng Sanatorium 1955).

In 1960, a mobile team was set up for case finding and surveying prevalence. The team was composed of five technicians of the HD hospital. Each month, the team visited one HD clinic in one of the counties of Taiwan. The mobile team found quite a few new patients in the first several years. For the first three years, the team found 1297 new cases. In 1963, there were totally 3288 registered patients, including 1105 inpatients and 2183 outpatients (Losheng Sanatorium 1963).

The mobile team kept records of patients, including the biographical information of the patient, change in individual cases, death, and the type of HD each patient had. Starting from 1960, the HD hospital updated patients’ records every month. Every half a year, the hospital made statistics based on the records, which provided a basis for making HD policies. According to the statistics, the number of new cases each year decreased from several hundred in the early 1960s to less than one hundred in the 1970s. In 1972, the objective of the prevention program became to decrease the number of beds so that more funds could be used for outpatient clinics and for training personnel working at these clinics (Losheng Sanatorium 1973).

**REORGANIZING MEDICAL WORK TO INTEGRATE THE RATIONALIZING TOOL**

In this section, I analyze how medical work was reorganized in order to integrate SSS as a rationalizing tool. I will show that medical work changed in terms of the social location of work planning, administrative status structure, and content of administrative communication. Overall,
the medical work of the HD program became more bureaucratic. Restructured as such, the new medical work allowed SSS to align clinics, paramedical workers, and DDS into an association that was aimed at delivering DDS and eventually eradicating HD.

I. Social Location of Work Planning

In the current HD prevention program, work planning took place outside of the majority of the work process. Previously, a physician treating HD would observe the symptoms and signs of individual patients throughout the process and adjust the treatment according to the development of illness in the individuals. In the new HD prevention program, physicians specializing in HD were still important. But they were important in the initiation of, rather than throughout, the work process. When paramedical workers or local physicians suspected a person to have HD, they would refer the patient to physicians specializing in HD. The specialized physician, by giving a diagnosis, would decide whether or not to initiate the treatment.

The majority of daily work was done by non-specialized workers, including paramedical workers and non-specialized doctors. After the diagnosis, the work was more standardized. The mobile team or the local medical workers would visit the patient periodically to give SSS examinations to make sure that the patient was improving. At the HD hospital and the local clinics, there were nurses who took care of the wounds of patients. The HD hospital was also equipped with physicians and surgeons. These physicians and surgeons were not trained specifically in HD, but were there to treat the wounds and common illnesses (Losheng Sanatorium 1955).

In the early 1950s, Dr. Chao and one other physician who previously worked in the HD hospital were the few local physicians specializing in HD. After Dr. Chao left the HD hospital
for a general hospital, both the HD hospital and that general hospital were able to give the
diagnosis of HD. Locally, both public health bureaus and HD clinics sponsored by the Taiwan
Leprosy Relief Association\textsuperscript{1} were responsible for referring patients. The local medical workers
were also responsible for dispatching DDS. A mobile team composed of a physician and several
medical technicians working at the HD hospital would make visits to one of the clinics each
month to give examinations.

The new order of medical work emphasized the effectiveness of DDS more than the
expertise of medical workers. The objective was to discover new cases and to hold existing cases
until they were cured. Underlying the HD prevention program was the assumption of the
effectiveness of DDS. The default situation was that patients would eventually be cured. This
type of work was continued until today. Specialized physicians who give diagnoses of HD do not
execute the daily work of treatment. Each year, specialized physicians and technicians gather to
talk about the active cases. The duration of the follow-up was decided to be five years. At the
2009 Conference for HD Cases it was decided that “After deciding a case to have completed the
treatment, the health bureau in charge of the case should still follow up every half a year and
continue the follow-ups for five years. That is, until the case is closed because of the completion
of control or death” (Center for Disease Control, R. O. C. (Taiwan) 2009).

\textit{II. Administrative Status Structure}

In the HD prevention program, there was a group of medical workers in administration who did
not legitimate by their status the information they processed. Starting from 1954, medical
technicians working in the laboratory of the HD hospital had been giving SSS and keeping
records of the results. They also gave training for medical workers at the local clinics. These
medical workers filed the results of SSS examinations, but they did not initiate them. The records were initiated by the diagnosis of specialized physicians and were used for their decision makings.

III. Content of Administrative Communication

SSS facilitated bureaucratic work by producing information that was formalized. Each patient had in their records the results of SSS in the form of BI, ranging from 000000 to 666666. These records served as approximations of the effectiveness of HD for individuals patients. The statistics made based on the records facilitated the evaluation of the overall effectiveness of HD prevention.

Statistics of prevalence rates showed that the disease was diminishing. In 1970s the new cases each year were less than one hundred. The policy became to replace inpatient beds with outpatient clinics. In 1986, the HD Prevention Committee in Taiwan estimated that the HD prevention program could be integrated into the general health services and there could be no specialized facilities for HD (Taiwan Provincial Government 1986).

USING SSS FOR BUREAUCRATIC NORMALIZATION

In this section, I illustrate how SSS provides a bureaucratic normalization for the misfit between the formal rationality and the substantive formality of the HD prevention program. Like bureaucratic administration in the case of mass production (Stinchcombe 1959), the bureaucratic administration of the HD prevention program was insensitive to product mix. The disease framework underlying the HD prevention program remained silent to the situation of sickness without pathogens. This rupture between the formal rationality and the goal of eradicating HD
became more obvious as the patients who were still sick with lingering symptoms outlived the tenures of medical workers and became the majority of residents in the HD hospital. The continual execution of SSS examinations filled in this gap of meaning by enacting the patients as cases in need of monitoring. But this convenient explanation, rather than reflecting patients’ experiences, made patients’ experiences even less invisible.

I. A Rupture between Formal and Substantive Rationalities

There has never been a perfect fit between the bureaucratic administration of the HD prevention program and its goal of lifting segregation. Like other bureaucratic administrations, the bureaucratic administration of the HD prevention program was not sensitive to product mix. When conducting case finding, the HD prevention program registered all the patients, including patients whose HD was at early stages and those whose HD was at advanced stages. It made no distinction between newly established cases that really needed monitoring and cases of patients who were cured of pathogens but not cured of the symptoms.

When the HD Prevention Committee was making decision about future HD policy, what was important was the number of new cases of the year, and the number of existing cases. There was no intention in making distinction between cases that had existed for decades, and those that were newly established. Moreover, the HD Prevention Committee suggested that patients could be discharged after being noninfectious. But it did not suggest concrete methods to deal with situations in which patients volunteered to stay. When the patients insisted that they were still sick, the non-specialized medical workers were not equipped to force patients to leave. Patients who were cured of pathogens but still sick thus remained “cases” in the program.
Patients remained cases not just as a practical result of the HD prevention work, but also for a bureaucratic reason. The current HD Prevention Committee and the HD hospital are staffed by doctors who have understood HD as a categorical entity. Under this framework, a person either has HD, or does not. This framework is silent to situations of patients who were cured, but still sick. On the other hand, the patients have a lot of diagnoses such as neuropathology, deformity, or wounds. These require medical workers to work for them. But according to current disease framework, what they have is not HD. In the early 2000s when there was a debate of whether to merge the HD hospital with another hospital, the decision was to keep the HD hospital to take care of the patients. For the hospital as a bureaucracy, it became a convenient solution to classify the patients as cases under monitoring.

In an interview, a technician expressed his awareness of the paradox: “It only makes sense to give the examinations when there are new cases. WHO suggested several years ago that there’s no need to do the examinations. CDC knows WHO’s opinion. But they have to consider the standpoint of the hospital.”

As illustrated in Chapter Two and Chapter Three, patients who were still sick volunteered to stay because of stigma and disabilities. The current HD regimes do not provide a language for explaining what happened to them, since the bacteria in their body were already purged. Patients were still sick. But according to the disease framework underlying the current HD practices, what they have is not HD. At the same time, they were treated as cases in need of monitoring. Cured but still sick, and treated as cases only in a bureaucratic sense, patients found their experiences made irrelevant.

II. Enacting Patients as Cases in Need of Monitoring through Annual SSS Examinations
The HD hospital has kept patients who were cured but still sick under the name of case holding. This requires the constant enacting of the fact that the patients might be released. In July 2012 the HD hospital again gave the annual SSS examination to the patients. The SSS examination was combined with the annual health examination.

**Figure 4-1. Technicians’ tools for conducting SSS**

When the patient sat down in front of him, the technician had already made his tools ready. He had spread on the table a bottle of alcohol cotton ball, another bottle of dry cotton ball, pens, blades, and tubes.
The technician had also taken out slides for the smears. A night before he used a marker to draw four squares on each of the slides. He also made tags with the birth date, the living area, and the name of each of the patients.
Figure 4-3. Technician doing a smear

Source: Photo taken by author.

While saying “now I’ll be making the examination for you. It’ll hurt just a little bit,” the technician used a scalpel to make a small cut on the skin of the patient.

At the time when receiving the examination, the patient in this picture told the technician that he was worried about a patch on his nose. He was wondering whether it was a sign of the relapse of HD.
After each smear, the technician wiped the scalpel against the slide in one of the squares, sterilized the blade, and then made the next smear.

Source: Photo taken by author.
In total the technician made four smears, from the skin areas near the right eye brow, the left eye brow, the right earlobe, and the left earlobe.
Figure 4-6. Technician collecting scalpels

The technician also used a forceps to take the blade from the scalpel and put it in a tube. Then he put a tag on the tube and collected all the tubes containing blades in a bag.

Source: Photo taken by author.
The skin smears, the blood samples and the blades were all put in the box and brought back to the laboratory. In the laboratory, the slides were stained with blue and red dyes.
Figure 4-8. Positioning slides under a microscope

Source: Photo taken by author.

Then the technician put the slides under a microscope.
Figure 4-9. A slide under a microscope

Source: Photo taken by author.

Under the microscope, the bacteria would be red and the regular cells would be blue. Watching his slides, the technician said: “We knew that they will all be negative.”
The technician updated this year’s results in the computer system.
Like last year, this year’s results were all negative. The technician said: “The exam did not have many effects other than making sure that they were negative.”

Despite that the technicians felt that the SSS examination did not make substantive senses, it did do at least two things. First, it justified patients’ protracted hospitalization. Patients had felt that they were still living with HD. The current medical framework of HD emphasized the pathogen of HD rather than its manifestations in individuals and thus did not reflect patients’ experiences. The annual SSS examination filled in this gap of meaning by enacting the patients as cases under monitoring. SSS provided a convenient explanation for patients when they felt the
need to explain their protracted hospitalization to outsiders, family members, or even to themselves. When presenting themselves to outsiders for the first time, the patients usually mentioned that they had been receiving examinations and had had negative results. However, this was not without drawbacks. Patients’ experiences were made invisible. Moreover, in some cases, patients did become worried about relapse.

The second thing SSS did was that it facilitated further transformation of the hospital. The patients would eventually die. But the infrastructure needed to morph into other forms in order to be able to handle future jobs. The carrying out of the periodic check-ups helped the transformation. According to the hospital accreditation schema in Taiwan, a research report would boost the possibility for hospitals to change from a non-research hospital to a research hospital. A physician who used to work at the HD hospital had recently developed research interests in a gene called HLA which was related with immune functions in human bodies. Aimed to test the hypothesis that the clinical types of HD were systematically related with the types of HLA, the physician was going to analyze the blood samples of the patients.

The centrality of SSS in the infrastructure is going to change too. Medical workers used SSS to introduce a new tool using genetic technologies. The blades used in the SSS examinations were going to a laboratory of the Center for Disease Control (CDC), where a new method for detecting HD was being established. The idea of the new methods was to use polymerase chain reaction to duplicate rapidly the genes of *M. leprae* contained in a specimen taken from the skin of a patient. After separating the genes of *M. leprae* and comparing their sequences with the sequences of the genome map of known *M. leprae*, the method would give the medical examiner information regarding both the existence of *M. leprae* and whether the *M. leprae* existing in the patient body belonged to the drug-resistant strain (World Health Organization, Regional Office
for South-East Asia 2009). The smears of patients served as samples for testing the new method. A researcher of the CDC laboratory said: “In the scientific disciplines, if we are to establish an examination method, we need to first have a procedure based on the typical strain of bacteria or virus. Now we already have such a method [referring to the method recommended by WHO]. What to do next is to show that this method works in the field. So you need to have a large number of samples to enter this procedure to test it. This way you know the extent to which the result of the examination conforms to the results on the clinic side. Then you can tell the physician, now I have this method available. If you have new cases in the future, I can provide a method that is able to detect [the existence or not of drug-resistance] correctly for, like, 80 or 90 in every one hundred cases.”

CONCLUSION: THE RECURSIVE RELATIONSHIP BETWEEN THE JOB AND THE TOOL

In this chapter, I have shown how the same technology that was used for picking up patients is now used to make mainly bureaucratic senses. I have analyzed what SSS attempted to accomplish, how medical work changed to fit SSS, and what senses SSS made to current medical workers and patients. I have shown that SSS aimed to rationalize medical work for the HD prevention program in Taiwan. To adopt SSS as a rationalizing tool, the HD prevention program had particular arrangements in the social location of decision making, the authority status structure, and content of communication. Overall, the HD prevention program became more bureaucratized. Despite that the HD prevention program had been effective, there has not been a perfect fit between SSS and the goal of the HD prevention program. SSS shifted the focus from symptoms to bacteria, and from the particularities of individual patients’ experiences to the
eradication of HD in the whole population. This ontological framework of disease underlying the HD prevention program was silent to experiences of patients who were cured but still sick. The current use of SSS filled in the gap of meaning by providing a bureaucratic justification. At the same time, however, SSS made patients’ experiences even more invisible.

This process of mutual shaping of tool and medical work is illustrative of the concept of bureaucratic normalization, by which I mean the process through which the rationalizing tool of an institution introduces not just a way to organize the routines of work, but also a normative order to what counts as the institution’s job. A tool can provide one standardized method of calculation which the routines are based on (Stinchcombe 1986). But what this tool really accomplishes is a result of mutual shaping between the job and the tool (Berg 1997). It may gradually become difficult to describe those experiences that fall outside of what came to be the institution’s job after the institution adjusted its job to allow the tool work.

In the case of HD prevention program, SSS provided one way to rationalize the program’s work. But the rationality was not something given. Rather, it was a choice made under a particular context. Moreover, the routines of work were arranged in particular ways to allow SSS work as a rationalizing tool. When there was only a limited amount of funding and personnel, it was more efficient to use SSS to bureaucratize medical work rather than to tailor the treatment to individual particularities. In this way, the same medical workers could manage a big amount of cases. In this particular context, delivering the treatment to as many patients as possible became what defined the job of the HD prevention program.

Both patients and medical workers today somewhat feel that current use of SSS makes little more than bureaucratic senses. But this feeling is difficult to articulate given that SSS has proved to be effective, and this fact has become what defined the institution in which patients
and medical workers find themselves. Medical work and patients do a lot to maintain the illusion that the tool and the work still fit each other and to justify their respective roles in the terms of current use of SSS. The patients were managed as if they still needed monitoring. For the hospital, this provided an account for the protracted institutionalization of treated patients. For the patients, this provided an account for their life in the institution.

So the bureaucratic procedure was full of ritualistic meanings for various actors. Participating in this ethnomethodological moment of HD control allowed both the patients and the medical workers to legitimize their respective roles. It hid the built-in gap in the infrastructure and made patients’ lingering symptoms appear like just a coincidence or personal misfortune. Doing SSS continually provided a convenient way for both medical workers and patients to reconcile the paradox that patients were cured but still sick.

SSS did facilitate the rationalization of medical work for the HD prevention program and improve the overall effectiveness of the program. It also provided a justification of patients’ institutionalization by framing the patients as cases in need of monitoring. But at the same time, the adoption of SSS as a rationalizing tool was not just pragmatic but also normative. The rationalization emphasized HD as a specific disease. It defined the pathogen as the authentic disease that required intervention. As such, the same rationality that led to the overall effectiveness of the program had made patients’ experiences invisible.

When patients’ experiences and actual medical work are brought back to the story, it becomes less obvious whether the rationality that defined the HD prevention program, an otherwise effective program, is efficient. Defined as cases in need of monitoring, patients are vulnerable in multiple senses. Patients spend time doing the SSS examinations each year. In addition, some of them worry about the relapse of their diseases. Most importantly, patients have
been seen as the ones who were responsible for their own illness. Defined as cases that are not yet closed, the patients’ membership is defined from a negative orientation. This crack of meaning where patients find themselves was built-in to the HD prevention program. However, the current disease framework is silent to their experiences. The HD prevention program rationalized by SSS is the healthy’s infrastructure and is the sick’s topic. It prevents the healthy from becoming sick or restores the healthy state if they become sick. In contrast, it responds to the sick’s need by fitting them into a regime that was not designed for them. Treated by the same preventive medicine, the HD patients-to-be-diagnosed and the HD patients already sick experience the disease in different ways. In this medicine, the HD patients-to-be-diagnosed experience HD as a treatable disease, while the HD patients already sick experience HD as a disease that was treated too late.

Endnotes

1. The Taiwan Leprosy Relief Association was established in 1954 by foreign pastors and doctors along with local ones. The Association helped bring to Taiwan volunteer medical workers, medications, and funding for HD (http://www.tlra.org.tw/). Starting from 1960, the six HD clinics originally sponsored by the Association along with 17 other clinics set up by the HD Prevention Committee or public health bureaus served the function of outpatient clinics for HD (Losheng Sanatorium1963).
CONCLUSION

THE PARADOXICAL EXISTENCE OF PATIENTS REVISITED

This concluding chapter is composed of three sections. In the first section, I summarize the main argument of each of the four substantive chapters. The most important message is that for individual patients, a cure that is otherwise effective may channel them into a limbo state in which they alone are responsible for the social and physical consequences of the disease. In the second section, I discuss the concept of orphaned patients in light of the patients studied and argue that the concept is helpful for studying situations in which medicine, instead of saving people from consequences of a disease, transforms the consequences. Finally, I revisit the paradoxical existence of patients and conclude by a suggestion for improving current HD medicine for patients living in the HD hospital in Taiwan.

SUMMARY OF CHAPTERS

In the four substantive chapters, I followed the gradual constitution of DDS as a cure for HD, the ways in which patients’ body-biography trajectories evolved after receiving DDS, how patients shaped their environment in a way that allowed their bodies to function, and how paramedical workers produced biomedical markers that made bureaucratic senses but did not reflect patients’ lived experiences of the disease. The most important message is that to the patients I studied, a cure that was otherwise effective actually channeled them into a limbo state in which they alone were responsible for the social and physical consequences of the disease.
In Chapter One, I introduced the concept of the configuration of cure. DDS became an effective cure when physicians believed its efficacy, found a way to induce its efficacy, and attributed the efficacy to it. When physicians used DDS to individual patients, this efficacy had to be retrieved. The retrieval involved a rearrangement of disease classification and bureaucratic organizations. The concept of the configuration of cure emphasizes that the material characteristics of a substance alone does not determine its function. Rather, a substance becomes part of medicine when reclassification of knowledge and rearrangement of medical work are aligned in a way that allows the substance a role.

In Chapter Two, I combined the stigma literature and the discussions on body-biography trajectories to illustrate how patients still live with stigma resulting from the interplay between new medical understandings of HD and their body-biography trajectories. I emphasized that the coping strategies of the stigmatized ones can actually be stigmatizing in the long run. As infection, rather than symptom, became what was institutionally understood as the disease, patients still having lingering symptoms after treatment lost the credibility to make complaints based on their symptoms as well as entitlement to the care the HD hospital provided. For patients having visible symptoms, what they faced was the conundrum of whether to return to previous communities where their disease was not understood, or to find some way to have their symptoms framed in medical terms. For many of them, living as a patient was less discrediting than living at home, where they would be totally dependent. Embracing the identity of a patient justified patients’ use of hospital care, and explained for patients’ exemption from previous social roles. At the same time, however, patients found that HD patient became their main identity. The social lives on the inside became difficult to be turned into credibilities outside of the patient community. Unlike chronic illness patients who “come back” to previous social roles,
the narratives patients collectively created helped patients embrace, though ambivalently, a patient role.

Chapter Three illustrated patients’ coping strategies for living with disabled bodies on a daily basis. The strategies involved paying attention to what happened to the body parts when the body parts were subjected to forces or thermal energy as well as the subsequent effects of the body parts on the environment. They also included striking a balance between using the body in everyday activities and preserving the body, and receiving therapeutics that may or may not help the impaired bodies. To highlight patients’ effort to keep their bodies functional, I propose the concept of the “body mechanical”—a set of practices for keeping impaired bodies functional and accommodating medical treatments with everyday lives. In the same way that diabetes patients enact the body as a metabolic system, the patients I studied, in trying to live with bodies without sensation, enact the body as mechanics. Through trial and error, patients found ways to coordinate the multiple elements involved in particular activities so that the body works to serve the individual. The body mechanical sees disease as a normal aspect of life. And it tries to be flexible in the local situation. Practicing the body mechanical, patients strive, though sometimes also fail, to establish a configuration of body-environment, so they can go about activities such as cooking, going to church, grocery shopping, and attending a tea table.

Chapter Four explained how the same technology that was used for picking up patients is now used to make mainly bureaucratic senses. I have shown that to adopt SSS as a rationalizing tool, the HD prevention program was reorganized in various ways. Overall, it became more bureaucratized. Despite that the HD prevention program had been effective, there has not been a perfect fit between SSS and the goal of the HD prevention program. SSS shifted the focus from symptoms to bacteria, and from the particularities of individual patients’ experiences to the
eradication of HD in the whole population. This ontological framework of disease underlying the HD practices was silent to experiences of patients who were cured but still sick. The current use of SSS filled in the gap of meaning by providing a bureaucratic justification. At the same time, however, SSS made patients’ experiences even more invisible. This process of adopting SSS illustrated how the rationalizing tool of an institution introduces not just a way to organize the routines of work, but also a normative order to what counts as the institution’s job.

A FIRST STEP IN CONCEPTUALIZING ORPHANED PATIENTS

As the case of HD in Taiwan shows, the actual effects of a treatment involve a balance between public health and individual wellbeing, a balance that must be locally negotiated by patients and medical workers. Redefining HD as an entity that can be managed by a bureaucratically organized apparatus, DDS treatment was effective in eradicating HD from Taiwan. But it also facilitated the formation of a group of orphaned patients.

Drawing on the Taiwanese case, here I discuss the four general features of orphaned patients. Orphaned patients are cured but still sick, and are permanently bereaved of the care they need. As such, orphaned patients are fragile in the senses that their wellbeing is contingent on the direct environment they live in and that they are subject to bureaucratic interventions. Emphasizing the limbo state that is rooted in medicine, the concept of orphaned patients, instead of focusing how medicine saves people from consequences of a disease, focuses on how medicine transforms the consequences.

I. Orphaned Patients Are Cured but Still Sick.
Orphaned patients are born in a medicine aimed more at delivering service to many people at the same time than improving the wellbeing of individual patients. In the case of breast cancer (Aronowitz 2007), heart diseases (Aronowitz 1998; Greene 2007), and fibromyalgia (Barker 2005), medical and social responses to diseases transformed the diseases’ clinical and population-level meaning as well as patients’ experiences. Certain knowledge and clinical experience than others were made irrelevant. Similarly, in the case I studied, DDS treatment defined the pathogens that would lead to infections as the relevant disease. After receiving the treatment, HD patients were cured of pathogens but not cured of the physical consequences of the disease. Despite that patients were still sick, in the DDS regime, what they were actually sick with was not what would lead to a diagnosis of HD. In this way, to the patients, treatment differentiated disease identity and illness identity.

Orphaned patients are turned by medicine into recipients of medical service, but have not received service that would stop them from being in need of medical service. The situation orphaned patients find themselves is characterized by a misfit: They are actually ill, but there is no medicine to treat them. This is the kind of misfit that is the side-effect of order-building (Bauman 2004). Living in a limbo state that is rooted in medicine—a “social homelessness” (Bauman 2004) in a sense—orphaned patients are like orphans whose parents are unknown.

II. Orphaned Patients Are Permanently Bereaved of the Care They Need.

For orphaned patients, the effect on their body-biography trajectories is permanent. Observations of career, work order in hospitals, and chronic illness process have shown that time is socially patterned into cycles (Hughes 1971[1945]), trajectories (Strauss et al. 1985), or turning points (Abbott 2001). And social institutions such as school, job market, and marriage often program
life episodes with a capacity for self-regeneration and self-perpetuation (Abbott 2001). Despite unintended, the medicine that treats orphaned patients programs body-biography trajectories with such a capacity for self-regeneration and self-perpetuation.

The HD patients I studied illustrate this point. Despite formal understandings of HD and illness experiences of later patients changed drastically because of the adoption of DDS, things have not changed a lot for these patients. Patients before DDS simply were ill until they died in an almshouse or in the sanatorium. They experienced an unfortunate life event that no one was able to change. Patients who obtained the disease after DDS would not develop the advanced symptoms of the disease. Only for patients who were given the cure when the consequences were already irreversible did their sickness become the limbo state where they were cured and still sick. In the betrayal funnel observed by Goffman (1961) in the case of mental illness, the desertion by family and friends was initiated by family or friends as they tried to return to their own life. In the HD case, patients initiated the retreatment into the hospital because insisting on staying in hospital not only provided care, but also provided a license for patients to be exempted from previous social roles. At the same time, however, the social lives in the hospital became difficult to be turned into credibilities outside of the patient community. Through a process of stigmatization (Link and Phelan 2001), the life event of contracting HD became one that directed patients’ body-biography into a trajectory that is irreversible. Falling in the crack between cure and illness, social homelessness became patients’ lot.

III. The Wellbeing of Orphaned Patients Is Contingent on the Direct Environment They Live In.

Because in the medicine in which they are recipient of medical service there is no compartment reserved for them, orphaned patients’ wellbeing is contingent on the direct environment they live
in. Orphaned patients enact a body that at the same time allows them to go about daily activities and to be a recipient of institutional help. The cure that could bring patients back to the state before having the disease does not exist. But orphaned patients learn to recognize that this is irrelevant to them. Instead, orphaned patients develop a style to be adaptive and resilient.

In the HD case, patients arranged the temporal and spatial orders of their everyday lives in ways that they could accommodate the many requirements of conducting everyday activities and receiving medical treatments. In a similar way atherosclerosis patients enact the “body multiple” (Mol 2002), patients I studied lived with the “body mechanical.” Patients who feel pain in legs when walking but not when resting go to a hospital to have a diagnosis and treatment plan. Despite that it is the same body that links the clinical and the pathology departments, patients find that there are multiple realities of their body. In the outpatient clinic and in the pathology department, different aspects of the body are assembled into particular realities relevant to the respective sites. Diagnosis and treatment plans emerge when incompatibilities among the different realities are worked out (Mol 2002). To cope with the physical consequences of the disease as an everyday reality, HD patients make explicit considerations of the mechanical principles of their body and direct environment. Unlike the enactment of the body multiple in atherosclerosis clinics, the enactment of the body mechanical is not for the purpose of coming up with detection and treatment of a disease. Instead, the purpose is to have a configuration of body-environment that allows patients to go about activities such as cooking, going to a church, grocery shopping, attending a tea table. Patients take risks in these daily tasks and are prepared that, once the configuration breaks down, they will need medical interventions and will need to find a new configuration.
IV. Orphaned Patients Are Subject to Bureaucratic Interventions.

In sharp contrast to the close attachment between body and environment for orphaned patients, the work of medicine providers is featured by social distance. The work medicine providers do serves more to make bureaucratic senses than to provide substantive help to remove the disease for orphaned patients. This distance, however, helps medicine providers maintain a mentality required for the work of taking care of strangers (Rosenberg 1995).

In the HD hospital, there is an anachronism resulting from the continual use of SSS examinations. SSS did facilitate the rationalization of medical work for the HD prevention program and improve the overall effectiveness of the program. But at the same time, SSS emphasized HD as a specific disease; it defined the pathogen as the authentic disease that required intervention. Having had negative results of the SSS examinations for many years, patients do not need the examinations to make sure that the disease is removed. But to the hospital, which defined patients as cases under monitoring, it makes bureaucratic sense to continue the SSS examinations. As such, the same rationality that led to the overall effectiveness of the program had made patients’ experiences invisible. The seemingly simply technological activity of SSS examination actually serves the highly ritualistic function of providing justifications for the HD hospital’s bureaucratic arrangement and patients’ protracted institutionalization.

CONCLUSION: THE PARADOXICAL EXISTENCE OF PATIENTS REVISITED

This dissertation studies a group of patients who were cured but still sick; free to be discharged but voluntarily remaining hospitalized. The disease has been eradicated from Taiwan for a while, but the lesson is still relevant. Patients who live with contested illnesses (Barker 2005), illnesses
without symptoms (Greene 2007; Timmermans and Buchbinder 2010), or remission (Frank 1995) each reflect particular conundrums brought about by the otherwise effective diagnosis or treatment measures in modern medicine. Adding to this anthology of modern patients, orphaned patients remind us how much is required of patients to stay functional even after they are cured. Moreover, there are multiple relationships between a cure that is institutionally defined and the wellbeing of patients. For patients, the pursuit of cure might not be the single most important thing. No less important are the acknowledgement that illness is a normal aspect of life and strategies to cope with life with illness.

As “orphaned patients,” HD patients in the HD hospital in Taiwan do a lot to be adaptive and resilient. For these patients, HD is not something they once had and having been removed from their bodies. It is something that they have lived with by seeking medical help, by creating jobs and relationships with fellow patients, and by managing the body that is neuropathic and can receive wounds constantly. The social psychology involved is very different from the time when segregation was required. During that time, patients either reluctantly became hospitalized or voluntarily sought hospitalization out of despair. In the current medicine, DDS does help. But it does not save HD patients from consequences of the disease. Instead, it transforms the consequences. Patients started to learn to manage the strange situation of being cured but still sick.

These orphaned patients I studied thus touches upon the question of equity, an important question asked by interactionism in the form of “cui bono?” (Star 1991) and by empirical philosopher Anniemarie Mol when discussing “good enough” medicine (Mol 2008). In the Taiwanese HD case, the HD policy with DDS as a cure was installed with the good intention to save people from HD. Medical researchers and practitioners did their best to work out this
intention. But who actually benefited from it? How do we determine whether the medical service provided is good enough?

This dissertation provides some clues for considering this question. The HD medicine using DDS as a cure was effective in eradicating HD from Taiwan. But it did not have the effect of reversing the illness that already took place in individual patients. The definition of HD as a disease that could be cured by DDS continued to inform the way HD medicine is organized. As such, for the patients who are cured but still sick to continue to receive the care they need, both patients and medical workers have to emphasize the importance of the disease that was once in patients’ bodies. As a result, although patients’ effort of being adaptive and resilient comprised part of what keep patients’ impaired bodies functional, the efforts was underappreciated. It is in this medicine that patients whose HD was already at a more advanced state became orphaned patients—patients who live in a social homelessness due to their illness.

It is out of the range of this dissertation to suggest an alternative policy for HD prevention. However, the dissertation provides a perspective for possibly improving the current medicine for the HD patients studied. Seeing from the perspective of this dissertation, there can be more constructive ways to organize the structure of today’s HD medicine. Patients’ illness could be seen also as a normal way of being sick with HD. Efforts to reconcile the fact that HD has already been eradicated from Taiwan and that there are still HD patients in the HD hospital can be reallocated to taking care of HD patients who are still suffering from the disease. The case of HD suggests that acknowledging the normality of pathological bodies can be a constructive way of arranging social life.
I started accumulating field notes and analytic memos right after I entered the field site in October 2009. In this appendix is a memo I completed on January 25, 2010. In this memo I included excerpts from previous field notes. I also started analyzing data. Some of the analyses in the memo became the basis on which I developed later analyses. Some I decided to be less relevant. Recapitulated or not in the dissertation, the interactions I documented remained an important mnemonic device that helped me recall the figures and events in the field site when I was trying to organize the analyses into a narrative. The excerpts, analyses, footnotes, and pictures were in the original memo. The only editing was the replacement of names with pseudonyms to remove identities.

[Memo, January 25, 2010]

Below I firstly talk about the different traits of interaction when the elderly leprosy patients are with others and when they are with outsiders. Then I talk about two common and yet contradicting themes in the narratives of the leprosy patients. I also talk about how the themes are manifested—both in the ways people with different life trajectories make sense of their lives and in the ways people react to the medical professionals.

**INTERACTION TRAITS**

I. When Old People Are Together
Seeing each other every day and without many news happening in the community, some of the topics people talk about are recurrent. Three examples are: food, children, and death. The discussions on these topics usually lead to recalling of memories or reflection on one’s self.

1. Food

Sitting together in the physical therapy room, people exchange recipe and talk about where to buy food materials and the price of food, either from first-hand experience or from the news. Occasionally an old man calls a vendor selling various sea foods to the hospital. News as such is also announced in the physical therapy room so that people know the time and location to do the shopping. Eating is at the same time a necessity and an event in the community. When there are important holidays, people eat together. Then the eating becomes a topic to talk about the next day.

To mark the end of a year, a feast was held in the square in front of the church on December 27. The catering company built the tent one day before the feast. On the day of the feast, they brought all the equipments and created a temporary kitchen.
In addition to the patients and their families, the pastor and his family, two physical therapists, and some nursing assistants also attended the feast.

Growing up during or right after the Second World War, people of this generation in Taiwan have the experience of living at the subsistence level. Thus being able to afford food is equal to being able to make a living. People who bring them food are seen as very kind and caring. When talking about the missionary who established the Presbyterian Church, several people mentioned that she brought flour, “batta” (butter), and “jeezu” (cheese) to them. Given that life was difficult at that time, the taste and nutrition of the sustenance is so unforgettable that they mentioned it warmly.

The talk on food usually evolves into talking about memories. In these occasions people do not need their audience to agree or comment on their utterances. The mere existence of the audience
Excerpt from January 21, 2010 in the physical therapy room in the morning.

Prompted by a patient’s comment on the price of green beans recently, H talks about a dish fotiauchiang that was served on the feast on December 27.

H: What I like most in fotiauchiang is taro. But that day there were only three pieces in the dish. Why were there so few? It’s not something expensive.

A: The container is not big enough for that. There are too many ingredients. My fotiauchiang is even better than what you can get in a restaurant.

H: I went to many restaurants with our sisomi\(^1\) in the past. Once we had beef that was really tender. I think they soaked the beef before cooking it.

A: What we did in the public kitchen in the past is to soak meat in soda water. To make meat tender you need to do that.

H: In terms of food, Yuanshan is the best. However, despite that it is so beautiful, its restrooms are surprisingly dirty. There was another occasion in which a guy guying dogs from me treated me to a meal at Guobin. He said it’s yumcha (literally “drinking tea”; an alternative name for dim sum). I said I don’t drink tea. He said you just come here and you’ll know.

A: Yumcha is dishes coming in small portions.

H: Not just that. They also have regular dishes. He intentionally arranged that for me. He also ordered Cantonese congee for me. Mine is beef congee. His is sea food congee. That guy did beef and pork business in Kowloon and made a lot of money from the business.

Analysis

In this excerpt H mentions his experiences of going to some expensive restaurants, which were

\(^1\) A kind of band that specializes in music for funerals. There used to be such a band composed of HD patients in the hospital.
made possible by his job as a saxophone player in a *sisomi* and his dog business with a guy from Kowloon. Because the *sisomi* band went to many different places, as a member H has many stories about what he saw and tells those stories often. His experience of doing business with a guy from Kowloon also seems to be a worth mentioning experience for him. Kowloon is an area in Hong Kong and thus the business counts as international.

A mentions her experience of working in the public kitchen, which was responsible for making food for people in the sanatorium in the past. On another occasion she has mentioned that she was proud of what she did in the public kitchen. She applied her expertise in cooking to her job and got positive feedback from people. Also she suggested the kitchen make congee for people who are very ill so they do not die from not being able to eat.

Food is loaded with memories for both H and A: what they did in the past that made them proud of themselves. Despite that the talk about a dish starts with discussion on the component or the format of food, it evolves into a talk about memory. When H was talking about taro in *fuotiaochiang*, A used the conversation to assert her expertise in cooking. The same happened when they were talking about *yumcha*. A commented on *yumcha* by saying that it is dishes coming in small portions. But H used it to talk about his relationship with his business partner from far away.

2. Children

When the patients, especially the women, are together, they talk about other people’s children. From these children’s stories they come up with conclusions about one’s fortune.

*Excerpt from January 21, 2010 in the physical therapy room in the morning.*

K: Do you still remember Y’s son? Y has good fortune. Her son is good to her and he does not fear (the disease).
A: Each one of our children here is healthy.

K: And their children are healthy too. …If the child fears the disease he is not good.

G: A’s second daughter has good fortune.

K: She got married with a man from Y.

G: But the first daughter is pitiful. She was sold to be a prostitute.

K: She said she would come back to visit her mother only after her father’s death. The father is so cruel. He sold her as a prostitute. …Y has bad fortune. She did not like the guy her mother introduced to her and instead wanted the guy she met and with whom she fell in love. This guy was not better.

A: That’s her own fortune too.

K: You’re right. …Y’s son has grown up now. He keeps asking money from his mother. Her mother tries to save money but the efforts are in vain in the end.

Analysis

According to these patients, whether a woman has good fortune is judged based on whether her marriage and her children bring good life to her. The reverse might also be true: that marriage and children are the result of one’s fortune—things that happen beyond a person’s controls. The story of Y is used to confirm this view—despite that she tries to pursue her own will, her fortune weighs over her efforts. The desire to pursue one’s own will is not appreciated. Instead it is the result that counts. The same view also persuades one to simply accept the result, as is manifested by A’s comment on Y’s story: “That’s her own fortune too” and by K’s agreement.

Instead of spreading news about what is happening in friends’ lives, these talks are more like reviews. The stories of A’s daughters and of Y seem to be familiar to these women. When one initiates a story, others add to it with the details they know. In the process of reviewing and
commenting on these stories, they again confirm their beliefs about fortune.

3. **Death**

Previously I have observed that death in the community serves these social functions: an occasion to review customs and how prestige is allocated in the community, a reason to be busy and to get together, a topic for chatting, and stimulation for people to reflect upon themselves and to think about how they would face their own death. The example below illustrates these points.

*Excerpt from December 2, 13, and 14*

On a Wednesday morning an old and a middle-aged women, both in black, enter the physical therapy room. The old woman picks up towels packed in boxes from a paper bag in the hand of the middle-aged woman, and gives them to some people in the room.

When going to another room, S bumps into two other women sitting on the chairs in the hall way outside of the physical therapy room.

S: Did Elder Liu die?

K: It’s been several days. You didn’t hear it from people?

Z: Whatever you want to know, you just come here. People come and go here and you can hear anything. It’s like a *hongsangdai*.²

K: You come here everyday and yet you didn’t hear it from people?

S: I saw her crying yesterday. You have given her the white envelope?

K: It’s because we gave it to her so we got this (picks up the towel packed in a box on her knees).

Z: The person’s still here and she gave us this. Usually you receive this only when the person is sent out. They’re the only people who give the towels when the person is still here.

S: Did you give the envelope to her in person? Are they coming again tomorrow?

² Radio station. The term Z uses here is archaic.
Z: You don’t need to give her by yourself. You can give it to L.

K: L or M, either is fine.

Z: He’ll send the envelope for you however many you give him. Just be sure that the money is in odd number. Now there is one person missing and so the number shouldn’t be even.

K: You only make the number even when it’s something to be celebrated.

S: I got it. Thanks.

Ten days later on Sunday the funeral is held in the church. After the worship in the morning people who are to help with the funeral stay in the church. At the same time when the choir is rehearsing a song written by the pastor, people from a funeral company arrive at the church and move flower baskets with name tags into the church.

People start to come after 12 pm. They go to a table under the tree outside of the church, give a white envelope to the receptor, and got a towel. The receptor writes down the names of those who give the envelope and collects the envelopes to give the family afterwards.

Under the tree M is talking to a visitor.

M: We live in the children’s dorm when we were children. At that time you were already a young lady. You came to visit your cousin. That’s when we saw you. You were in about the same stature. Somewhat fat. Right (turns to T who is to her left)?

T: I’d say chubby.

A man comes to the chairs under the tree and sits next to L.

L says: You haven’t been here for eight years.

Seeing another man coming, L says: This one hasn’t been here for 30 years. What kind of wind blows at you and brings you here today?

The man: The wind blows at me every day. So the people living on the ninth floor sent a flower
basket?

Referring to the first man, L says: This is the elder one in our “kindergarten” (referring to the children’s dorm).

The second man: Did elder Liu ever live in the children’s dorm?
L: No. He’s already an adult at that time. All those who are elder than I did not go to the children’s dorm.

The first man: I’m number 577. What about you?
L: I’m 600.

Because the two men talk with each other loudly, L says: Hey, please, be quieter.

The first man: This is something to be celebrated. He was recalled by God. You can’t judge this by a secular view.

L: That’s right but still you should show some respect.

More people come and some remain outside to talk with each other in front of the church. When it is almost 1 pm the receptor sees the coffin coming. He asks people to stand up. All the people on the outside enter the church following the coffin. There are more people than the seats in the church and so some people have to sit in a building next to the church where there is a screen playing what is going on at the funeral.

After the pictures of Elder Liu and his family are played, Elder Wu reads a passage that summarizes Elder Liu’s life, starting with the date and place Liu was born, the date he came to Losheng, the date he was baptized, and the date he got married. Liu is described as a person who is very committed to his job, the church, and his friends.

This passage quotes Liu’s own words on his 81th birthday: I feel satisfied with my life. I thought I would be a clerk in the small town where I was born. I was not able to foresee all those
happened to my life and contributed to what I have now. This is God’s will. God has been good
to me. I feel grateful and satisfied.

Then the passage ends by saying: ‘Shengwang is in Losheng; Losheng has Shengwang’\textsuperscript{3} is
talking about Elder Liu. He has left his footprints in this place, which is the final home to him.
Just like Dr. Dai Rensho is burred in Bali and Pastor Sun and his wife were buried in Shilin,
Shengwang and Losheng are the starting point for Elder Liu’s new life and the destination for
him.

After Elder Liu’s son expresses thankfulness to people attending the funeral, the funeral
ends with two elders covering the coffin with a flag representing the church, and with four young
men moving the coffin out of the church.

Most people leave the church after the funeral. Only some friends and the family go to
the crematorium in three busses arranged beforehand. When people are at the crematorium, the
coffin is already being burned. People stand in front of Elder Liu’s picture in a circle, with the
pastor in the middle. The pastor says a prayer for Elder Liu and has people sing a hymn together.
He says it’s a hymn that Elder Liu likes a lot. Then the pastor gives the flag to the wife of Elder
Liu. The daughter of Elder Liu cries.

The family stays at the crematorium to wait for the bone ash urn. Most people dismiss after
arriving at the church, with only the church co-workers staying at the church. After taking a rest
in front of the church, people move to the memorial pagoda where the bone ash urns are stored.
The pagoda is on a hill in the sanatorium. Inside of the building is a big hall. The three sides of
the hall, from floor to ceiling, are used as the storage space for the urns. Each of the space is a
small cubicle that is gold and has a door and a number on the door. The pastor picks up a magnet
from the table next to the door to the hall and uses it to try the doors of several cases on the right-

\textsuperscript{3} A slogan coined by the pastor. Shengwang is the name of the church. Literally “holy hope”.

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hand side. He picks the one that is at about the height of his chest and says: This one is good. The door is easy to open. After the space for Elder Liu’s bone ash urn is determined, several people consult a table on the wall that has the names of the deceased and the number of their respective cases. Then they go to the case to make sure that the urn is in the right place. There was a relocation of the urns recently.

When waiting for Elder Liu’s bone ash urn, people talk outside of the hall.

M: How do you call Elder Liu?

Man: We call him uncle. Are you familiar with him?

M: Elder Liu and his wife were the managers of the children’s dorm when we were living there. They were very caring to us.

W, a boy about 5 or 6 and the grandson of a patient, finds a piece of shredded snake skin on the grass and tries to call his mother to see. Not getting his mother’s attention, he picks up the skin and shows it to people, causing objections from several young women who say that it is disgusting.

A car comes and from the car come the family members of Elder Liu. Elder Liu’s son holds the urn and the eldest grandson of Elder Liu holds Elder Liu’s picture, walking next to his father. Elder Liu’s daughter walks by the side of Elder Liu’s wife. When people are inside the hall, the pastor says to the family: I have picked this space for you. It’s easy for you to see him. Elder Liu’s son puts the urn into the case and closes the door. People stand in a circle and sing again the hymn that Elder Liu likes.

On the outside of the hall when waiting for the cars to be arranged, people talk with each other. The little boy W busies himself by running around.

Elder Liu’s daughter tells W’s mother: He resembles his father very much.
W’s mother: You’ve known him before?

Elder’s Liu’s daughter: Yeah, we’re familiar with each other. He indeed resembles his father. And both are mischievous.

Before people get in the cars, Elder Liu’s daughter thanks everyone for helping with the funeral and says that they would not have known how to do it without people’s help.

In the car W calls Elder Liu’s wife: Liu nainai (grandma).

Without turning her head, Elder Liu’s wife says softly: Thank you W, you’re a good boy today.

Then she remains silent on the way back to the hospital.

Next day in the physical therapy room in the morning, Elder Liu’s wife asks J and K whether they got the towel.

K: You’re so considerate. But don’t worry about that.

Sitting next to me, N tells me: She’s the widow of Elder Liu.

After a while K says: P, you should take care of yourself. Don’t get sick; that’s not good.

It’s good fortune for him to leave earlier.

H: Yeah, it’s good fortune for him.

J: Once he’s there he does not have anything wanting.

K: He’s not like us, the living, who are bewildered. …Though people who don’t understand would take me wrong and think that we’re celebrating his death.

Seeing the physical therapist Bo standing next to her, K says: Bo laushu,⁴ did you see it yesterday?

Bo: Yeah, I did. I saw the parade composed of the cross, the pastor, and the choir.

J: He’s like a duaguang (one who has a position in authority).

⁴ In Taiwanese shu refers to someone who is a professional. Laushu actually means teacher. But I suspect it is because there is no such a term to refer to physical therapist so they use the term laushu.
Bo: Dauguang (dried tofu)?

J: (laughs) No, I said duaguang.

Bo: I have never seen that flag.

J: Me either. It’s only for Elder Liu. He contributed a lot to the church. There won’t be things like yesterday from now on.

While H is talking about some stories he witnesses in the crematoriums in the past, Bo laushu talks loudly to a woman sitting in a wheelchair and having a tube in her nose. She looks old and stiff, with her head tilted to one side.

Bo: Ohiyo (good morning in Japanese)!

Woman: Ohiyo.

Bo points at Kiku and asks the woman: Who is she?

Woman: Kiku.

K: Oh, excellent.

Bo: Who am I?

The woman says something softly. Hearing it, Bo says loudly: A servant? Everyone in the room laughs.

J: She also says L is a servant last time.

K: Sing the song for her. The one she likes.

Then K sings: Xiongde de jiaogo lee (God is taking care of you)…

She stops and says: It only works when Bo laushu sings.

Bo sings: God is taking care of you. Every day he is taking care of you. Every day he is indicating the direction for you. God is taking care of you. God is taking care of you.

When Bo is singing, the old woman sings with him and nods her head, which remains
tilted, along with the rhythm.

After finishing the song Bo asks the woman: Is God taking care of you?

The woman says: Yeah.

People in the room smile.

K says: And another one, that one she also likes.

I ask K whether H was talking about stories he learned from working as a member in the *sisomi*. K says yes. Then she talks about some activities in the sanatorium such as costume drama. She says: It’s fearsome when you reflect on it. People are dying very fast. Her words are interrupted by Bo’s voice.

Bo: Ajiong!

Hands on his knees and bending his body to the height of Ajiong, Bo sings another song. Ajiong again sings with Bo. Sitting on a chair facing Ajiong, Elder Liu’s wife also sings with them and nods her head slightly along with the rhythm. After finishing the song people in the room smile again.

K says to me: The lyrics say that the grace of God suffices for her.

*Analysis*

The funeral itself is an event for the community members. To prepare for the event, a committee needs to be organized, people need to take up various roles, and order flowers, towels, and snacks for the funeral. Because this time the deceased is a prestigious person in the community, so the funeral is made extraordinary by the flag representing the church, the song the pastor wrote, and the four young men who help move the coffin. The funeral attracts a big number of community members to attend. On the next day, some community members are curious about how an outsider (Bo *laushu*) feels about the funeral.
On the day of the funeral, when various people are busy, P (Elder Liu’s wife) is the person who remains quiet. She simply appears, walks in the company of her daughter, and receives the flag from the pastor. In the car she turns down the invitation to talk from the little boy W, with a baseless comment on how he does that day. Because on some later occasions where I see her she appears to be a warm and mildly humorous old lady, I interpret this as a statement that she is keeping her feelings to herself. However the funeral is not meaningless to her. The next day she asks her friends whether they receive the towels as a way of making sure that the funeral is appropriate—despite that she actually already gave the towels to them in person ten days before the funeral. This I interpret as evidence that she sees herself as a host and is responsible for the expectations of the guests. Also the funeral makes her publicly become a widow and legitimates, or obliges, her to receive consoling words from her friends.

The togetherness of the community not only facilitates the change in the social role, but also creates a sense that things other than the change in the social role remain the same. On the next day of the funeral, P is already part of the daily interactions in the physical therapy room. By the time of a trip to Taipei City on January 10, she is already a person who gives me the impression to be a warm and mildly humorous old lady.

II. When Outsiders Are Present

Because the restitution for the patients is already made and most of the patients have already moved into the new building, there have not been protests on the streets for the community. But “Hansen’s Disease Human Rights Group”, established in early 2009, is still functioning. The group is composed of professionals from medicine, law, and history, the superintendent of Losheng, officials from the Department of Health and the Council for Cultural Affairs, and
representatives elected among the patients. College students are still going to the sanatorium on Sunday afternoons to meet with the representatives. At the tenth meeting of the group on January 15, in addition to the official members of the group, the students are also present. Two engineers from the rail road company are also invited to the meeting, because one of the agenda of the meeting is to discuss the possibility of building a sidewalk on the road that is presently used by the trucks of the rail road company.

At the meeting the proposal of the sidewalk was illustrated by a graduate student. Other subjects in the agenda were discussed among the professionals and the officials. Two patients made statements on some of the subjects. Their statements did not reach the chairman directly but instead went through the interpretations of the professionals and the students.

In a talk with a patient, U, who is still living in the sanatorium and has been connected with the activists, she mentions some of her experiences with the students. During the time when there were protests, she wrote some songs which were used in the protests.

Excerpt from January 18

I wrote the songs not for myself, but in the hope that people can live better. The vice superintendent has been caring for us. He said he’s just doing what he should do. But I don’t take him for granted. I feel grateful for him. I also feel grateful for the pastor. He doesn’t fear and he’s caring. People should have other people’s needs in mind. For example we went on the street. Some people say we are encourages and hope us to keep going. But some people say we’re asking too much. Now part of the sanatorium is reserved, it’s the result of our efforts. And it’s not easy to have restitution from the state. I was there I know it’s not easy. One should be grateful for everything.

It hurts me to see that students were dismissed by the police with force. Some of the students
sold their properties for the protests. I’m touched by that. But some people say we were used by the students. It was energy-consuming to participate in the protests. Now I’m trying to let it go. At the beginning there weren’t many students, but there were more and more. And some professors came, some other people came. Gradually we got stronger. Some people are more radical; I sing.

I told the students that you know these old people are leprosy patients but you are still here. You must have good will. And you are not the kind of children who do not know how to communicate with parents. …They have contributed a lot to us. So I think they have different values from other young people. It’s not possible if it’s not because they are caring. But I told them that in addition to coming here they should also spend time with their parents. At that time when I saw the police try to force the students to dismiss, I felt bad. We wanted to protect the students and the students wanted to protect us. That’s how the affection was built.

I have modern ways of thinking. I know what the young people are thinking about. Sometimes my son tells me: what you say about before is outdated. In the past the parents are commanding. Nowadays things are different. You need to respect children. I feel that children nowadays are different. Sometimes I ask my son to take up some tasks and he does not do them right away. I told the students that they need to learn to understand their parents. And they should try to serve their needs. Some students tell me that it’s good to talk to me and they learn a lot from me. I told them that’s because I have modern ways of thinking. I know how to communicate with young people. Like some people lamented that nowadays young couples walk hand-in-hand or even hug each other on the streets. I say you don’t need to watch. Everyone can have his own opinion.

Analysis

U labels both her son and the students as young people. However she generalizes her experiences
with her son and with the students in different ways. From her experiences with her son, she gets the conclusion that time has been different. Her son’s reaction to requests from her is not what she expects. What she learns from her own experience with her parents is that children are expected to obey. But this set of knowledge is not applicable in her relationship with her son. She attributes this un-fulfillment of expectation to time, a factor that is out of control.

On the other hand from her experience with another subset of “young people” she gets the conclusion that despite that time is different she is able to communicate with young people. In front of this subset of young people, she plays the role of an instructor and has the opportunity to teach the lesson that is not welcomed by her son.

THEMES IN NARRATIVES

I. The Situation

Most of the patients are in their seventies now. People in this generation in Taiwan live their childhood during or after the Second World War when most people live at the subsistence level. They then live their adulthood during the 1960s and 1970s when Taiwan was undergoing rapid industrialization. Now in their later life stage, the life styles of their childhood are extent. The transformation in the social environment stimulates people in this generation to conclude that “time is different”.

Despite sharing this experience with other people in this generation, the leprosy patients are distinctive in their life trajectories, which are shaped a lot by the disease. Stem family has been the main stream in Taiwan since the colonial period. In 1977 (that is, when a person who is 70 now was 37), 72.9% of the people who have married children lived with one of the married
Thus it is very possible that a person who was 37 and was married in 1977 would expect to live with his parent(s) or her husband’s parent(s). But this is not the case for a person who was diagnosed as a leprosy patient and was institutionalized. A leprosy patient who was 37 in 1977 was more likely to find his or her life trajectory as such: growing up in a stem family, living his or her adulthood in a period when most contemporaries who are not leprosy patients live in stem families, and living in one of these situations: 1) single 2) married without children 3) nuclear family.

1. Single
Because men are more susceptible to leprosy, there have been more men than women in the sanatorium. Among them, those who are not veterans from mainland China are more likely to get married. Most of the female patients were married. Among them, the majority were married with people who are also patients.

2. Married Without Children
Among those who were married, the couples who got married in the early period of the community were influenced by the policy of sterilization. But some of the people who were influenced by the policy adopted children or kept close relationships with children whom they took care of for other people.

3. Nuclear Family
Among those who were married and had children, the majority live in a nuclear family. Because a person who is diagnosed as a leprosy patient is not a welcome member of the family, it is rare

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6 An exception is the couple who sells vegetables. The husband in this couple, when he was at age 2, was adopted by a family who did not have children and was the only child in that family. After getting married, he and his wife (also a patient) live with his mother.
7 When the Nationalist regime lost the civil war to the Chinese Communist regime in 1949, it brought with it a big number of people to Taiwan.
that a parent would choose to live with this child.

Being diagnosed as a leprosy patient and institutionalized channel people into certain life trajectories and social relationships. A leprosy patient might not maintain relationships that are produced by family life in the same quality and quantity as their contemporaries who do not have the disease. Substituting these relationships is relationships with medical professionals, other patients, and religious professionals that are brought about by institution life.

II. Two Main Themes in Narratives

1. Sense of Exploitation or Regret

The source of the sense of exploitation or regret ranges from the deformity of body, the deviation from the mainstream life trajectories, to dissatisfaction with one’s own family. A lot of time the sense of exploitation or regret is attributed to the disease and the arrangements based on the disease.

2. Gratefulness

At the same time there is the imperative to be grateful. This is an important theme of the pastor’s sermons. The pastor interprets people’s sense of exploitation or regret as the result of their focus on living rather than life. He has encouraged people to be grateful for everything happening to their life, including, and even especially, for the disease. He tries to persuade people that the disease is a blessing in disguise, a reminder for people to pursue spiritual life. The imperative to be grateful is not simply imposed by the pastor. People do follow the imperative and execute it in various ways.

3. Contradiction

The sense of exploitation or regret and the imperative to feel grateful are not easily reconciled.
The pastor provides a way out of the contradiction by proposing an oxymoron—that the disease itself is a blessing. But this idea is not always self-evident to people. Instead people have developed various ways to deal with the contradiction.

III. Making Sense of Life Trajectory

Here I give one example of a person who is single, two examples of people who were married without children, and two examples of people who were married and lived in a nuclear family. I explore how they make sense of their life trajectory and how the themes mentioned above play into the sense-making.


F is now 77 and has lived in the sanatorium for 60 years. He was diagnosed with leprosy at the age of 10 but did not enter the sanatorium until the disease became serious when he was 17. The disease left lesions on his fingers, toes, and nose. Talking about his childhood he says: I didn’t have the courage to play with other children when I saw them playing. People didn’t dare to come close to us when my family were harvesting water oat in the farm. My face was strikingly ugly. And he commented on institutional life: Life is happier here—you have leprosy and I have leprosy. Otherwise the whole family was damaged. It’s better that I’m here. In the sanatorium we caught rabbits (for sale), gambling, day after day. We just want to live happily.

The happiest part of the institutional life seems to be those related with the female missionary. F says: She came here to give sermons and teach people singing hymns. She does not fear the disease even though there weren’t drugs. She came here to build roads and houses. We didn’t have clothes at that time. She went back to the US and told people about us. Other countries in the world, Britain, Germany, sent us sustenance. Milk powder, flour, *batta*, and *jeezu*.
Do you know what **batta** is? It’s fat from milk. **Jeezu** is a kind of nutritious food. It came in bottles. We had it with steamed buns (smiles).

Other than these details, Wu tends to talk abstractly. Actually he volunteered to tell me his story before I asked him to. He seemed to like talking to people and I was impressed by the efficiency with which he summarized the Bible. He also has his own theory of why Japan lost but the US won the Second World War.

F expressed his regret when talking about his brother: I was diagnosed with the disease at the age of 10. If there were drugs at that time, my hands and feet would have been intent. My brother got the disease from me. But he was cured by the drug. Now he has a wife, children, and grandchildren in society. He lives in Kauhsiung now. You wouldn’t detect his disease by his appearance.

Despite that not having a family is regretful to him and he attributes this to the disease and the lack of drugs, F does not criticize the institution. Neither does he think that the establishment of the hospital is something worth protesting. He says: I’m against the protest. If we protest against the relocation, the government can’t use the land. His attitude towards the institution—that it is for public welfare—is in line with the way he presents himself to me—a person who had witnessed special pieces of history because of the disease.

2. **Married Without Children: J and K**—the “good-enough” mindset

J and K are sisters who are at the age of 80 and 79, respectively. They were institutionalized in the colonial period and people have called them by their Japanese names. Despite that people know they are sisters, they are unhappy when people point out the fact, for it is not something good to be institutionalized. Both of them were married and both have no children because of the policy of sterilization. Both were retired elders of the church. In 2005 J went to Japan to tell her
story in Japanese in court. That her stories touched people in court and people congratulated for her because they won the case against the Japanese government became good memories for her. She says: The graduation trip of my elementary school was to go to Japan. My grandmother prepared the money for me. But she feared that people would notice my symptoms. So I didn’t go in the end. It didn’t happen to me that I’d have the opportunity to go.

Every morning when K receives physical therapy, she almost invariably greets a woman who does cleaning job by calling her: beauty! Also almost invariably she then comments on the woman’s creative clothing and says that “time is different”. Sometimes she elaborates on what she means by saying that “time is different” and says that nowadays young people prefer not to live with old people. Since she does not have children, I suspect this observation comes from stories of friends.

When discussing other people’s children (p. 4 of this memo), K has agreed that marriage and children is determinant of, or determined by, one’s fortune. On another occasion, she talks about a visit to a nursing home and comments that not needing to rely on children is a good way to live. She also mentions several times that throughout her life, it is now that she enjoys best fortune. As to the protest against the hospital, she expresses her disapproval and says one should feel grateful because the care provided by the hospital is good enough. Combining these clues, my interpretation of her sense-making is as such: Although in the abstract not having reliable children is something regretful, it is out of one’s control. Plus time is different and even though one has children, they might not want to take care of parents. Seen through this perspective, not having children but receiving appropriate care is something grateful. The idea of fortune in combination with her own life trajectory, mediated through the “time is different” observation, leads to the “good-enough” mindset as is manifested in her attitudes towards the protests against
3. Nuclear Family: A and U—the “altruist” mindset

A. A is in her mid sixties and entered the sanatorium in 1959. She got married with a patient and has two sons and a daughter. A used to work in the public kitchen and in the retail store in the sanatorium. She has been proud of her extra services for people when she was holding the positions. A’s husband killed himself because he became deeply in debt due to gamboling. A worked hard to clear the debt. In the end she not only cleared the debt but also was able to rebuild her house located next to the hospital. A tells her story in a regretful tone. The sense of regret comes from her husband (leaving debt to her and abusing her), her mother (leaving all her money to her son but not to A despite she has the disease), and her son (not showing respect for her despite that she has contributed a lot to her family). These factors are not necessarily related with each other but together they contribute to the way A reflects on her life. She has three different conclusions for her life: 1) I feel my life has been worthwhile because people have trusted me and gave me the opportunity to help them. 2) Due to the disease I never know what it means to be a young girl for my whole life. 3) (said on an occasion complaining to the pastor that she never knows what it means to be a young girl and receiving advice from the pastor to be grateful) I’m grateful because I have grandchildren, a house, and money that is enough for me. My only hope now is to live for another few years to make sure that my grandchildren have firm belief in God.

B. U is 66 now and entered the sanatorium in 1960 when she was 17. She got married with another patient and has three daughters and a son. She wrote several songs that were used in the protests. Recently she is still being invited to sing her songs in the protests for other groups. She says: We can’t just say that it’s none of our business. One shouldn’t be so selfish.
She expressed her feeling of exploitation because of the disease when she was in the streets with students. But in a talk with me she expressed more emotions due to the feeling that people living in the sanatorium are not receiving the same quality of care as those living in the hospital and that those who participated in the protests were said to be used by the students. Despite all these, her experiences with the students contribute to her self-esteem. She believes she is able to catch up with time. She is also proud of her efforts in the protests (p.11-12 of this memo).

Both A and U feel exploited because of the disease and being institutionalized. There is the thought that life could have been better if it was not for the disease. But both have also felt that their life is worthwhile because of what they did for fellow patients—through providing extra service or through going on the street.

IV. Reactions to Medical Professionals

The imperative to be grateful is manifested in the reaction to medical professionals. The vice superintendent has been a responsible and nice person. His being responsible and nice, in contradiction with the medical professionals in the past and seen through the lens of the idea of gratefulness, is interpreted more as mercy. This interpretation is manifested in the almost melodramatic scene created by the sudden news of his transferring to another hospital.

*Excerpt from January 13*

It is already past the time the vice superintendent should be in the rehabilitation department and so people have been wondering why he is not there. The wonder was dispelled when a nurse tells people that the vice superintendent might be busy with packing. It is until then that people know that the vice superintendent was assigned a position as a superintendent in a
hospital in southern Taiwan and is leaving two days later. S, a patient who lives on the fifth floor, feels hurt that she does not have the chance to say goodbye to him. She talks to M, who feels the same, and they decide to try to throw a farewell party for the vice superintendent in the afternoon. They also decide to buy a gold ingot for the vice superintendent as a present. They tell an administrative staff about the party plan. The staff then calls the secretary to make sure that the vice superintendent can come to the hospital at 2 pm. At the same time, S and M are busy with collecting money from people who want to take part in buying the ingot for the superintendent. By noon the time for the party is set and broadcast to people. Also S and M collect a name list of more than one hundred people who are in.

By 2 pm, the hall on the first floor is already full of people from the hospital and from the sanatorium. As a representative of patients M gives a bouquet to the vice superintendent. She tries to say something but fails to because she bursts into tears. The vice superintendent says that it is actually also a sudden news to him. He gets the news two days ago. On that day a patient asks him whether he is transferring to another place. He did not tell the truth because it was difficult to him to do so. The superintendent, the pastor, and the representatives from the Catholic Church and from the Buddhist temple take turns to talk about their reluctance to see the vice superintendent leave. Several patients also volunteer to go on the stage to talk about their feelings towards the vice superintendent. U reads the lyrics of a song she wrote for him, in which she says that every time she wears the rehabilitation shoes she thinks of him.

After the party, people take turns to take pictures with the vice superintendent. Both M and P cry. Vice superintendent pats D on her arm. She also cries. Sitting next to D, a guy says: It does take much time if you take the High Speed Rail. It’s better once you think this way. S walks towards vice-superintendent. She tells him: Let us know when you come back to visit us so that
we can see you. The vice superintendent says: I’ll be back again in two weeks.

After the vice superintendent leaves, S also goes back to the fifth floor. G goes to her room and asks her: Did you see that I took a picture with him? I’m very happy. M took it for me. She was going to take a picture of only me and the vice superintendent. But I said I want three of us in the picture. Talking about the last superintendent, G says: I took a picture with superintendent Huang too when he was leaving. I visited him when I went to Jiayi. The nurse still remembers me and comes to hold my hand. Three or four days ago I asked the vice superintendent whether he was leaving, he said no. He was talking about me today but I think he doesn’t remember my name. I told him if he is xiengguang\(^8\) I would not stop him. Otherwise I don’t want him to leave. G sighs and says: It’s difficult for us to keep a good doctor.

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\(^8\) Getting a promotion in the Chinese bureaucratic system.
REFERENCES


