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博士論文

# Technologies of Difference

Medical Practice and the Politics of Life in Contemporary Japan

## 差異としての技術

日本における慢性病と生の政治性に関する人類学的研究

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A thesis submitted to Osaka University (Department of Anthropology)  
in partial fulfillment of the requirements of the degree of Ph.D.



# TABLE OF CONTENTS

Abstract (English).....	v
概要（日本語） .....	vii
List of Published Chapters .....	ix
List of Figures .....	x
Note on Names and Romanization.....	xi

## INTRODUCTION: TOWARDS AND ETHNOGRAPHIC THEORY OF DISEASE.....1

1. Aims and objects .....	2
2. The problem: human affairs .....	3
3. Interlude: metamorphosis .....	9
4. More than one: medical things .....	10
5. Less than many: situating difference .....	16
6. The (not quite) multiple worlds of diabetes .....	21
7. The field.....	29
8. The chapters.....	37

## PART I: LEARNING DISEASE .....43

### CHAPTER 1. THE PLACE OF DISEASE.....45

1. Meanings, knowledges, practices.....	45
2. Purakutisu: places of theory .....	47
3. The Suzuran Diabetes Center.....	51
4. Looking for disease (in the wrong place).....	59
5. About the quiet old man who didn't know he was sick .....	60

### CHAPTER 2: METABOLIC ENCOUNTERS .....67

1. Patient education.....	68
2. Learning nutrition.....	69
3. Glycemic thresholds.....	78
4. Diagnosing complications .....	80
5. Between disability and health .....	88
6. Internal secretions .....	90

### CHAPTER 3: OF MUNDANE TECHNOLOGIES AND SENSING BODIES .....95

1. Medical technologies in practice .....	96
2. Diabetes and some mundane artifacts .....	99
3. Mi ni tsukeru .....	104
4. Hyperglycemia at your fingertips .....	107
5. Imaging fat and thick blood .....	117
6. Pills, needles, choices .....	126
7. Embodying differences.....	136



<b>PART II: COMPARING DISEASE.....</b>	<b>141</b>
<b>CHAPTER 4: TRIALS OF DIFFERENCE .....</b>	<b>143</b>
1. <i>Clinical trials: making difference</i> .....	144
2. <i>Recruitment: sararīman as a lifestyle</i> .....	150
3. <i>Lived facts of blood sugar</i> .....	157
4. <i>The metabolic syndrome controversy</i> .....	159
5. <i>The Japan Diabetes Complications Study</i> .....	163
6. <i>Inclusions: the new publics of diabetes</i> .....	165
<b>CHAPTER 5: ASSEMBLING VARIATIONS .....</b>	<b>169</b>
1. <i>From differences to assemblages</i> .....	171
2. <i>"Our thrifty genes"</i> .....	174
3. <i>The laboratory: experimenting with differences</i> .....	179
4. <i>Pharmacogenomic expectations and the problem of variation</i> .....	186
5. <i>Pharmaceutical values: the case of glitazones</i> .....	192
6. <i>Interferences: the adiponectin assemblage</i> .....	196
<b>CHAPTER 6: BIOSOCIAL IDENTITIES.....</b>	<b>201</b>
1. <i>The old-new politics of patient advocacy</i> .....	202
2. <i>"No doctors here:" The Kuromatsu Patient Group</i> .....	204
3. <i>Eating together 1: gaman</i> .....	209
4. <i>The stress of chronic disease</i> .....	217
5. <i>Eating together 2: school lunch</i> .....	220
6. <i>Commensurating disease</i> .....	222
<b>CHAPTER 7: METABOLIC TOGETHERNESS .....</b>	<b>227</b>
1. <i>Learning and comparing</i> .....	229
2. <i>Another politics of life: living together with the metabolism</i> .....	236
3. <i>Postplural anthropology as ethnographic theory</i> .....	242
Appendix.....	249
Notes.....	267
References .....	281

## Abstract (English)

Taking diabetes, a chronic metabolic disorder, as its ethnographic ground, this thesis explores the mediation between cultural and social worlds, medical technologies and the politics of life in contemporary Japan. To do so it departs from classic notions of disease and illness in medical anthropology and practice theory (*jissen ron*) to carving out *an ethnographic theory of disease* by drawing on current ideas in, and across, science and technology studies (STS), medical and cultural anthropology and Japanese studies.

Diabetes is a major health problem in Japan affecting more than 5 million people directly. Its public health implications grow along with the potential market of newer and simpler medications and diagnostic devices making it one of the most dynamic fields of collaboration between the state, scientific research and private pharmaceutical companies. My concern in this thesis is to describe how both mundane and advanced biomedical technologies perform these links, which, in turn, articulate biological and cultural differences by measuring, negotiating and comparing them in medical practices. Combining participant observation at a diabetes center in Northern Japan, and other healthcare and research facilities, with interviews of patients, medical professionals and public health officials, along with the assessments of endocrinological literature and popular media, the dominant pluralist model of medical anthropology will be criticized and corrected.

Differences play a crucial role in contemporary medicine, and anthropologists are, by profession, attentive to the plurality of illness and its social consequences. However, as recent dialogues between science studies and anthropology have shown, such plurality is present on both sides of the divide, and anthropologists should address them symmetrically if they want

to overcome both cultural and technological reductionism. Through an ethnographic engagement with the technosocial situations of diabetes care in Japan, the thesis explores two ways in which the metabolism and its disorder is acted upon: *learning* and *comparison*. Part I introduces a diabetes center where patients are treated for the prevention of diabetic complications. It deals with the emergence of mindful metabolic bodies by looking at the local sites of diabetes care where high glucose levels are embodied in an ongoing process of *learning disease*. Part II, by contrast, follows *diabetes as a comparative entanglement* between epidemiology, genetic science and public health interventions on a massive scale.

Different facts and experiences structure the knowledge about diabetes that emerges from the interferences of particular scientific and cultural attributes. The puzzle is this: how do the different subjects of clinical medicine, molecular biology and epidemiology come to stand for the same disease? Or, do they at all? The argument presented in this thesis contends that such interaction is made possible through the constant work of the metabolism. The final chapter deals with the question how biomedical technologies and innovations force us to rethink the fundamental anthropological problem of difference. Here, I propose the notion of *metabolic togetherness* as a mode to extend the ethnographic method beyond the notion of pluralism and diversity. Finally, I conclude that doing an *ethnographic theory of a metabolic disorder* is also a way of living together with the metabolism.

## 概要（日本語）

本論文は、日本における「糖尿病」という慢性疾患の民族誌を通じて、医療技術に介される人間と非人間の多様な関係を考察することで、人類学研究における差異の問題を問い直すことを目的とする。

差異と類似の評価は、現代医療の現場で極めて重要な役割を果たしている。医療技術の選択肢をめぐる、年々増大している多様化と共に、身体を生きる患者の生活における異質性も注目的になりつつある。こうした科学知識と文化における複数の差異を媒介するのは、身体を「公的表面」として生み出す医療のさまざまな人工物である。本論文で取り上げる糖尿病治療で使用する様々な医薬品と医療技術は、このような科学と文化の多様性を動員する人工物である。従来の人類学者はいろいろな角度から医療の多元性を描いてきた。西洋医学と異なる医療体系を記述した数多くの民族誌から、患者と医療者の種々の解釈への関心や、医学知見としての疾病と文化現象としての病いの対立まで、生物医療を囲む多様性の存在については、十分に分析されてきた。しかし差異は体系、信念、あるいは解釈だけではない。差異は実践の要素でもある。

第Ⅰ部では、病気の学習に焦点を当て、北日本のある糖尿病センターで行われる糖尿病治療の実践（第1章）を人類学の眼鏡を通してみていくことにより、薬や診断機器などの、科学と文化と身体のそれぞれのレベルにおける差異化を結びつける役割について検討する。ここでは、糖尿病治療において極めて重要な役割を果たす患者教育（第2章）とセルフケア（第3章）の事例を踏まえ、複雑化した社会における差異の技術的な媒介を示してみる。なお、医療実践の「中」で、いかに文化と自然における違いが同時に構成しあいつつあるかを明らかにした上で、多元性の人類学における主導的な論考を批判する。

第Ⅱ部では、種々の民族誌的ならびに科学的な材料をもとに、糖尿病研究と予防の三つの現場である臨床（第4章）、研究所（第5章）、患者会（第6章）で行われるさまざまな「比較実践」を描く試みを展開する。そこで生活習慣と儉約遺伝子という、糖尿病学のそれぞれ異なる標的を行き来する「代謝」（metabolism）の動きを追いかけていく。糖尿病などの慢性病を患っている多くの人々は、自覚されていない体内の働きを抱きつつ、日々の生活に不可欠な知識を習得していくなかで、さまざまな他者との距離をはかる人格を再構成していく。第4章で、働き盛りの中年男性の生活世界と血糖の検査値という一見異次元のようにみえるものの間を揺れ動く「生活習慣」の動的な性格を示す。そしてこの「生活習慣」が、生そのものを意味する儉約遺伝子の関与を得て、日本人という主体と創薬の対象の間を行き来することについては、第5章で述べる。

糖尿病そのものの民族誌から見えてくる「学習」と「比較」という二つの配置を互いに見いだす状況をここで「代謝としての共生」（metabolic togetherness）と呼び、生活と生物との相互包含関係に注目したい。最後の第7章で、こうした糖尿病研究の現場で増殖しているハイブリッドを通じて、人間と非人間の多様性が互いに関係しあい、影響しあうことに着目し、人間と科学の複雑で動的な相互干渉に取り組むポストプルーラル人類学の可能性を実験的に模索する。



## List of Published Chapters

既出一覧

The argument put forward in this thesis has had a long gestation period. It has been in the making for ten years of research and collaborative work. And while all chapters have been originally written for and later adapted to the line of thought that forms the basis of this thesis, some of them were also published as stand alone articles in the following publications.

Chapter 2 and 3: 「差異を身につける—糖尿病薬の使用にみる人間と科学技術の相関性—」 『文化人類学』 73(1):70–92, 2008。

Chapter 3: 「病気の通約——血糖自己測定の実践における現実としての批判」 『現実批判の人類学—新世代のエスノグラフィへ』 春日直樹編、pp. 203–224、世界思想社、2011。

Chapter 4: 「代謝を生きる—移動性をめぐる実験的考察—」 『文化人類学』 76(3): 288–307、2011。

"Entangled Knowledges: Three Modes of Articulating Differences in Clinical Trials" In *CARLS Series of Advanced Study of Logic and Sensibility*. Vol. 5., pp. 232–244. Tokyo: Keio University, Centre for Advanced Research on Logic and Sensibility, 2012.

Chapter 5: "The Adiponectin Assemblage: An Anthropological Perspective on Pharmacogenomics in Japan." *East Asian Science, Technology and Society* 7(2)261–28, 2013.

Chapter 6: "Attuning to Food: Tensions and Relations in Diabetes Care" In *CARLS Series of Advanced Study of Logic and Sensibility*. Vol. 4., pp. 325–334. Tokyo: Keio University, Centre for Advanced Research on Logic and Sensibility, 2011.

## List of Figures

Figure Int-1 Mapping the plural world of diabetes .....	22
Figure 1-1 The Suzuran Diabetes Center: old and new .....	54
Figure 1-2 Patient family tree .....	64
Figure 2-1 Meal table used by patients of the Suzuran Center .....	76
Figure 2-2 Learning to walk .....	92
Figure 3-1 Image of tools for blood glucose self-monitoring.....	110
Figure 3-2 Reading the senses .....	115
Figure 3-3 Disabled others and selves.....	119
Figure 3-4 Imaging diabetes .....	123
Figure 3-5 Putting medications on the body .....	132
Figure 4-1 Men, women, Japan, Europe (Diabetes textbook).....	155
Figure 4-2 Cut-off points for the risk of metabolic syndrome .....	161
Figure 5-1 The thrifty genes hypothesis .....	176
Figure 5-2 The adiponectin assemblage: animal tests .....	183
Figure 5-3 Sib-pair analysis .....	183
Figure 5-4 Different genes, different drugs, different people (Biobank Japan).....	191
Figure 5-5 Different body parts.....	191
Figure 5-6 The adiponectin assemblage: linking domains.....	195
Figure 6-1 Map of Tokyo (East) showing Kōtō-ward and Sunamachi .....	204
Figure 6-2 The Calorie Counting Chart (karorī keisan hyō).....	212
Figure 6-3 Assembling disease: calories, patients, cherry blossom .....	216
Figure 6-4 Senrin-cha [Advertisement] .....	220

## **Note on Names and Romanization**

All names in the main text have been changed to protect the privacy of informants, except for some public figures (e.g., Nakamura Yusuke) and company names that have not been subject of ethnographic investigation.

In Japanese, family name precedes the given name, and this order has been followed throughout this text including the list of References. Romanization follows Kenkyusha's New Japanese-English Dictionary, 5th edition (2003), a modification of the so-called Hepburn-system that was worked out by the American physician and translator James Hepburn (1815–1911) in the 19th century. Macrons (ō, ū, etc.) indicate long vowels, but they have been omitted in place names with standard English spelling, such as Hokkaido or Tokyo.

In those references that have been published originally in Japanese, the original name (written in kanji, and/or hiragana, katakana) was retained in order to help Japanese readers identify the author. Romanized versions have been added to the list of References at the end of the text.





## INTRODUCTION

# **Towards an Ethnographic Theory of Disease**

*Intensive difference, difference of perspectives, difference of differences. Nietzsche observed that health's viewpoint on illness differs from illness' viewpoint on health.*

—Eduardo Viveiros de Castro

The research that forms the basis of this thesis has been concerned with what many people in Japan and elsewhere have come to know as diabetes in the past roughly one hundred years. To be sure, it does not claim to be a historical account in a strict sense of the word. Its aim is of a different dimension: to describe a few radically different practices of this 'coming to know' as a set of fairly recent episodes that are linked by nothing else but their object, that is diabetes mellitus (*tōnyōbyō*), or elevated levels of sugar in one's bloodstream. The different ways of knowing and encountering diabetes are going to be invented in the numerous activities in which it is performed and made real: measuring the level of blood sugar in medical laboratories or at patients' homes, learning to inject insulin into the abdomen or arms in a hospital, quantifying the population at risk on computers and in academic journals (including anthropological ones), or planning one's daily calorie intake in a group of people suffering from the same disease. In other words, what I set out to accomplish here is an account of the technocultural becomings of diabetes in contemporary Japan within the relatively limited genre of ethnographic writing. It may sound like a minimalist approach. However, as I will argue in this Introduction, such a focused attention to knowledge

practices in and around medicine assumes nothing less but a reconfiguration of what both physicians and anthropologists use to call 'disease'. This will require some experiments and innovation.

## **1. Aims and objects**

The central thesis of the study goes something like this: disease is neither an entity out there that medical science is called on to capture, nor a discourse constructed in the minds of physicians and patients waiting for the anthropologist's well-intentioned interpretation. *Disease is rather an act of encountering the world. It is unveiled at the very same time when the knowledge about it is being established.* And, as one would expect, it keeps changing along with this transforming knowledge. Once again, the transformations that this study addresses are not historical events—neither breakthrough medications, nor revolutionary paradigm changes will be examined here—, but rather a few mundane adjustments between alternative techniques of blood sugar measurements at the clinic or comparative shifts between the genetic data of different species, ethnic or gender groups in molecular biology.

Which brings me to the second key issue of this thesis, which is more of a methodological kind: how do biomedical technologies and innovations force us to rethink the fundamental anthropological problem of difference?

Anthropologists have since the birth of the discipline been inclined to explore the plurality of human existence and the ways people construct their different cultural perspectives of a shared natural reality; they hoped to find these "differences" in sharply defined communities at small islands far from home or of ethnic and other minorities in their backyards. One can always find exceptions to such generalizations, of course, but for better or worse, the hallmark of anthropological inquiry has been up until today a focus on

human difference: a systematic study of the Other and a more recent interest in making the familiar strange (Adams 1998; Fukushima 2005a).<sup>1</sup> Nowhere is such humanism more evident and prevailing than in the social studies of medicine, which is largely founded on the critique of inhumanity in modern biomedicine and its epistemological backbone of the "universal human" (Lock and Nguyen 2010).

Diversity, however, as I will try to bring out below, is not only the anthropologically remarkable condition of living with and talking about diabetes, but also—and more importantly: at the same time—the technosocial consequence of treating, preventing and controlling its deterioration. Diabetes always, without exception, involves technological mediation and/or scientific practices: pricking fingers, walking with a pedometer, talking to *a* physician or *other* physicians, counting calories and calculating health care costs, eating, and, well, metabolizing sugar. Whether one is a patient, a researcher, or a bureaucrat, encountering with high blood sugar levels compels one to learn to see and feel the body in a new way producing multiple levels of difference.

The second aim of this dissertation then is to extend the ethnographic method beyond the notion of pluralism that, while questioning human difference, takes all other kinds of multiplicity for granted. Rather than taking diversity as the social condition of human life waiting to be anthropologically mapped, here I wish to experiment with difference by treating it as mediator between human and non-human worlds, between biomedicine, anthropology and Japan.

## **2. The problem: human affairs**

**TOKYO, 2002**—"No, I'm afraid we cannot apply for nursing care for your mother. You see, she doesn't have any disease." The social worker showed a

long list to the couple sitting on the other side of the table.<sup>2</sup> The list included all kinds of conditions from Parkinson's disease to chronic pneumonia that made one eligible for long-term home care by an expert nurse (*kaigoshi*). The couple looked quite disappointed and read the document once more very carefully just to make sure that they did not miss out anything. A disease, for example, that the elderly woman had, after all. But there was nothing.

The fact was that his mother was as healthy as an eighty-eight-year-old woman could be, except her high blood sugar levels, which she treated with daily insulin shots. Once a month, she visited this clinic next to a station called Monzen-nakachō in the Eastern part of Tokyo to receive her daily doses until the next check-up. But as things went lately, she kept forgetting the injection more and more often, that is why her son wanted an expert caregiver. According to the social worker, however, his mother was not sick, at least not in terms of nursing care.

"It's rather odd," the husband commented after we left the social worker's office, "because next door she was treated with her diabetes, and now they tell me that *she is not sick?*" Her wife nodded in agreement and told me how all her attempts to keep *okāsan* (mother) away from the dessert box ended up in a failure, so that now she, the daughter-in-law, was not even allowed to do the injection for her—something that had been quite common before. "So now it's all my fault if her disease gets worse."

This little episode from my preliminary fieldwork in Tokyo could be a straightforward invitation to the enduring debate in the social sciences and humanities over the politics of difference in contemporary biomedicine; of how definitions and the lived worlds of health and illness are implicated in social and political-economic orders (see e.g. Kohrman 2005; Lipphardt and

Niewöhner 2007; Rose 2007). The contrast between disease as the treatment of elevated sugar levels in the examination room and as a category of insurance policy in the social worker's office a few steps away aligns too neatly with the well-described tendency for people and institutions to turn family and other social matters into biomedical problems. This snapshot also seems to bring up the classic tension of medical anthropology between disease and the "social course" of illness (Kleinman 1986), where the latter is captured in the narrative of the wife about her stubborn mother-in-law who is getting more forgetful and more diabetic from the same boxes of chocolate—a midyear gift (*ochūgen*) from her friends.

Until relatively recently, there seemed to be a widely held consensus along a broad spectrum of disciplines that the objects of medical science and the social studies of medicine are two different things. This neat division of labor fitted well with the conceptual framework of medical anthropology that presumed doctors treating *diseases* of the body on the one hand, and anthropologists—or social scientists in a broader sense—investigating the semantic complexity of *illness* and the social locus of suffering on the other.<sup>3</sup> Since the adoption of this so-called narrative model as the quintessential mode of doing medical anthropology,<sup>4</sup> a great deal of research has focused on revealing what lies on the other side—or behind, depending on the locus of the analysis—of biomedicine: patients with their own unique explanations of suffering (Das 2001), alternative ethnomedical systems (Leslie and Young 1992), or even embodied experiences that are incommensurable with the language of disease (Csordas 1994).

To be sure this notion of *illness* is a venerable and powerful argument. Take AIDS, for example, one if not the most studied disorder in the social sciences. The medical textbook says *it is caused by a virus*. However, when

anthropologists go out to do fieldwork, they talk to people who will tell them completely different things. That it's a problem with gays, or of their own stressful life (Biehl 2007). Yet others will explain it as a conspiracy between governments and the pharmaceutical industry (Fassin 2007). Even those sociologists who dare to enter the ivory tower of science will return with many different explanations that do not necessarily add up (Epstein 1996). There is just too much variety out there to be ignored. The anthropologist, of course, knows that *HIV is caused by a virus*, but she is after cultural difference.

But if so, she is not alone. Alongside, and often in tandem with, this anthropological pursuit of culturally diverse perspectives on illness, there has been an increasing ethical concern in the global North with the ill effects of medicalization. The infinite variation of ethnomedical practices and concepts that anthropologists kept reporting about provided a strong impetus for many social critics to refuse what they considered as the biomedical notion of disease, a fabrication that in the name of efficacy seemed to slowly, but steadily eat away the diversity of human experience.<sup>5</sup> As debates over the inclusion of 'culture-bound syndromes' into the third edition of Diagnostic and Statistical Manual of Mental Disorders (DSM)<sup>6</sup> during the 1980s, or the difficulties of medical development projects in some parts of Africa to deal with the common practice of female circumcision revealed, the diagnosis and treatment of human maladies are situated in local cultural practices and contingent political economies. In most social scientific accounts the abstraction of disease came to signify the opposite of rich cultural diversity, where difference was understood as the particularity of the observed and reported phenomenon in opposition to what well-intentioned—or not—psychiatrists and healthcare workers in clinical settings envisioned (Shell-Duncan and Hernlund 2000; Winzeler 1995). All these arguments have to do

with the broader and more dynamic social meanings of physical and mental ailments, and most of them point to the harm of medicalization<sup>7</sup> that the disease model is thought to foster in indigenous communities, social minorities, and eventually on all of us around the world.

Partly in response to these critical issues surrounding medicalization, many anthropologists since the nineties turned their attention to the generative potential of disease. They have been emphasizing different articulations of medicalization from scientific rivalry to popular protest. Allan Young (1995), for example, who had conducted his fieldwork in the specialized psychiatric unit of a Veterans Hospital in the U.S., claimed that the psychiatric category of post-traumatic stress disorder (PTSD) is a product of scientific and clinical discourses and the social demand to deal with soldiers returning from the war in Vietnam. Significantly for the argument I am developing, Young's analysis owes a lot to the Polish immunologist Ludwik Fleck who, in his pioneering work of *Genesis and Development of a Scientific Fact* (1935) showed how medical knowledge depends on the 'thought-styles' of scientists—on what their technologies, instruments and social constraints allow them to see (Fleck 1979 [1935]). In a similar vein, Young states: "the [conventional] genealogy represents the traumatic memory as a found object, a thing indifferent to history. Research into this memory and the associated pathogenic secret is portrayed as a process of discovery. I have argued for something else: the traumatic memory is a man-made object. It originates in the scientific and clinical discourses of the nineteenth century; before that time, there is unhappiness, despair, and disturbing recollections, but no traumatic memory, in the sense that we know it today" (Young 1995: 141). "Man-made," or not, we have come a long way since the times without PTSD. As Orkideh Behrouzan has suggested in the context of the Iran-Iraq war, such



medicalization of traumatic experiences becomes a way of life by turning diagnosis into cultural resource (Behrouzan 2015).

Kitanaka Junko (2012), from a different perspective, presents depression in contemporary Japan not as a scientific construct (although academic debates play an important role in her story), but more like a circuit of social protest and professional antagonism, when she writes: "Psychiatrists, through (...) legal disputes and mental health initiatives, are persuading Japanese that those who break down under tremendous social pressure may be victims of depression (*utsubyō*), an illness that until fairly recently had remained largely unknown among lay Japanese. Amidst the prolonged economic recession since the 1990s, psychiatrists have been urging people, with increasing effectiveness, to recognize their sense of fatigue and hopelessness in terms of depression" (Kitanaka 2012: 2). This tendency of linking biomedical knowledge to epidemiological outcomes has also been called 'biomedicalisation' to emphasize the ways self-governance as a mode of healthy seeking behaviour had been replacing the normative aspects of control in medical practice (Clarke 2010; Moyer and Nguyen 2016).

Whether it is culture or society, biomedicine or healing traditions, passionate scientists or helpless victims, the diversity of illness seems to be a result of negotiations, prayers and disputes by and between human actors. The political body emerges here as a biological discourse or a psychological narrative. As Lawrence Cohen notes in his rich ethnography of Alzheimer's disease in India, "at stake both in the voices of the old persons (...) and in the institutions and narratives through which these voices are heard is a multitude of repetitions" (1998: 7).

### 3. Interlude: metamorphosis

Indeed, such concerns are not so far from the original plan of my doctoral research. Encouraged by an ongoing public discussion of "the ageing society" (*kōreika shakai*) in millennial Japan, my initial plan was to understand the biopolitical logic of normal body in the context of chronic diseases. But as I hope it will be clear at the end of this thesis, anthropological problems, just like knowledges about disease, are always on the move (and, in this specific case, they are, quite significantly, entangled with each other). As a result, ethnographic projects end up pursuing quite different questions from the ones they set out to answer.

Inspired by childhood memories of my grandmother whose trips abroad had to be tailored to the prescription guidelines of insulin in a state hospital of the People's Republic of Hungary, I had some vague interest in how health and disease is something more (if not entirely different from) than what the doctor tells us. I knew from very early on that taking those shots once or twice a day is the easiest part of living with elevated levels of sugar in your blood. Finishing your holiday ahead of the others and leaving half of your cake on the plate was an entirely different matter. I somehow felt too, however, that cakes and nurses—as everything else in late-socialist Hungary—could be negotiated most of the time, when necessary. But the dilemmas remained: how much cake is too much? How long a trip abroad will make a person with diabetes suspicious in the eyes of the authorities? Where does the normal end and disease begin?

Years later, as my fieldwork at a diabetes center in Sapporo progressed, I started to realize that to decipher some logic of difference from all the diffuse and divergent talk around disease, I would also have to listen more carefully to the wide array of instruments and artifacts at the clinic that make those

discourses and narratives possible in the first place. Medical technologies spoke neither the semantics of suffering, nor the discourse of medicalization, but rather a sort of pidgin that mediated between embodied differences and scientific facts. Needles, CT scanners and diagnostic charts laid bare important connections between patients and practitioners, the clinic and the laboratory, or suffering and politics that are mostly inaccessible to everyday human language. It is for this reason that my focus has gradually shifted away from narratives to medical practices and the technologies of difference.

#### **4. More than one: medical things**

*"And in that instant of contact something was planted deep in my mind, something irreducibly mysterious, something quite apart from the danger that I had been in and the destruction that I had witnessed; something that was not a property of the thing itself but of the manner in which it had intersected with my life."*

— Amitav Ghosh

An ethnography of diabetes, admittedly, cannot easily discount the proliferation of things through which such a condition is engaged. The attention to the material adjustments in medical care is not solely due to an epistemological interest in how people come to know disease, but also a quest to understand how they learn to live with it. As things go in the multiple sites of contemporary biomedicine—from the neighborhood drug store to the maximum containment facility for infectious disease incidences—, it is more often than not through specific forms of technological intervention: needles, screening instruments, clinical trials and calorie meters, to name just a few.<sup>8</sup>

Drawing upon decades of scholarship in the field of sciences and technology studies (STS) and the ongoing discussions about the politics and ontologies of things at the intersection of anthropology and STS (e.g. de la Cadena et al. 2015; Henare et al. 2007; Latour 2005b; Mol 1999; Strathern 2004b), this thesis will explore how living with chronic disease, and especially with diabetes, follows the associations between heterogeneous entities through diverse activities including the technological mediation of this heterogeneity. This focus on medical *things*—both human and nonhuman, conceptual and material—will allow me to unpack the multiple sociotechnological assemblages and the more-than-human worlds of diabetes.

*Actor-network theory* (ANT) is probably the most well-known of the posthuman approaches that have been trying to challenge Euro-American assumptions about the straightforward separation of nature/culture, technological/social or human/nonhuman. More than three decades of debates, wars and ceasefires have left ANT more as a placeholder than a theory. But it is probably fair to say that its insistence on the agency of quasi-objects (hybrids) and the material-semiotics of translation together have succeeded in showing how human and non-human worlds, in practice at least, are intertwined through a continuous "netting, lacing, weaving, twisting of ties" (Latour 1996: 371). ANT has not only fertilized existing discussions around such core issues of anthropology as ethnicity (e.g. Candea 2010), cosmology (e.g. Holbraad 2012) or exchange (e.g. Maurer 2005), to mention just a few, but provided a language to both follow and account for the multiple enactments of reality.

The notion of *the ontological turn* in anthropology is, in a sense, an extension of this insistence on multiple realities building on the conceptual experiments of, among others, Eduardo Viveiros de Castro and Marilyn

Strathern.<sup>9</sup> The claim of this agenda—first laid down in the edited volume *Thinking through Things*—is that once we learn to take things seriously, the links between human and nonhuman realms emerge neither in material nor in representational forms, but rather in a methodological multitude through the "engagements with things as conduits for concept production" (Henare et al. 2007: 7). These arguments have been around for a while now and provided a fertile ground for exploring ideas across anthropology and science studies (e.g. Candea 2008; Carrithers et al. 2010; Gad et al. 2015; Ishii 2012). As others in Japan have further argued, such an ontological turn might be a positive answer to the epistemological critiques that have characterized anthropology since the 1980s and a return to questions of alterity and difference (Kasuga 2011b).

In tune with such concerns, the inaugural issue of the online journal *Hau* calls for a return to what they call ethnographic theory, or more precisely, to "ethnography as a pragmatic inquiry into conceptual disjunctures" (da Col and Graeber 2011). Following such a call, what better place to start a discussion of 'medical things' in Japan than the Japanese concept of *mono*, which, when translated literally, may stand for 'thing' in English. However, in contrast to the political connotations and the potential significance of gathering in public that the word 'thing' (*Ding*) in German and to a certain extent English carries with it, the Japanese term *mono* extends materialities in a different direction by signifying spiritual and ghostly worlds (Fukushima 2005b).<sup>10</sup> If we take Latour's advice to heart, the *conjuncture* between matters of facts and matters of concern that the word 'thing' designates turns into a conceptual *disjuncture* with spirits and ghosts as matters of concern in Japan (Jensen et al. 2016).

Now it is one thing that anthropologists will probably be the last to step back in front of ghosts and spirits<sup>11</sup>, but what does that have to do with disease and medicine in contemporary Japan? A little digging into the history of our discipline might be helpful here. The classic monograph by social anthropologist Edward E. Evans-Pritchard—a contemporary of Ludwik Fleck, mentioned above—, *Witchcraft, Oracles, and Magic among the Azande* (1937) has been an influential source of anthropological conceptions on disease. It is quite telling how the book has carved its place among the exemplary case studies of *social* anthropology, despite the admittedly central role of things— oracles, birds, witches—in the construction for disease etiologies. The Azande apparently know *what* causes disease, but they also explain *why* a certain misfortune befalls them. It is at this point where oracles—the most famous being *benge*, a poisonous substance fed to a live chicken—intermediate between common sense and mystical worlds by pointing at the witches who live among them. According to Evans-Pritchard, oracles in themselves "make no sense," it is the social relations surrounding them that provide the coherence of the system. One could argue, however, that it is the oracles that bring witches and people, "mystical" and "common" senses together in the first place. The Azande, as Evans-Pritchard clearly indicates, "*know* diseases by their major symptoms (...). The very fact of naming diseases and differentiating them from one another by their symptoms shows observation and common-sense" (482, 494–495; cited in Good 1994: 12–13).

While oracles can be, and has been, suggestive of the material aspects of social life, employing them here serves a different purpose much closer to what Marilyn Strathern (2011) once called bifurcation. She notes:

A feature of the kinds of bifurcations I am describing for Euro-American knowledge practices, specifically in social science, is that

distinctions easily contain or lead to other distinctions (either by replication of the same at some other site or by being brought in from a different dimension, as I just brought in the inside/outside distinction). (91)

Thinking through medical things then is a way to open up the obsolete methodological distinction in medical anthropology between the plurality of illnesses and the construction of disease, outlined above. To paraphrase the editors of *Thinking Through Things*, it is fair to say that such a methodological move will allow 'medical things' themselves to dictate the plurality of disease ontologies (Henare et al. 2007: 7).

In the past twenty years, ethnographically informed studies of medical science and practice in STS have been innovative in exploring such links between methods in the human sciences and medical instruments as they are employed in clinics, patients' homes and laboratories. Here, I will shortly introduce two influential concepts that helped to shape the empirical orientation of this thesis: "ontological choreography" and enactment.

In her posthumanist account of assisted reproduction, Charis Thompson (2005) has introduced the term "ontological choreography" to capture the fluctuation between notions of agency and reproductive technologies in North American infertility clinics. "Social categories and techniques," she remarks, "develop together and thereby change what life, parenting, and fertility mean in cultures with infertility clinics" (115). In the long—and more often than not unsuccessful—process of becoming parents, diagnostic and therapeutic technologies of assisted reproduction produce diverse worlds beyond that of race, class, or gender. What Thompson insists, in contrast to phenomenological and feminist critiques of in-vitro fertilization, is how medical technologies objectify their users in ways that lead, somewhat ironically, to subjects with agency.

Users and technologies animate each other. It is probably fair to say that ontological choreography is much closer to the Japanese idea of *mono*—where the line between lively and ghostly is blurred—than to Latour's notion of *Dingpolitik*. "We are familiar with thinking of technologies as motors of progress that produce or signal global stratification," Thompson writes "and as objects of consumption that differentiate the rich from the poor. But we are less familiar with the idea that our interactions with technologies—biomedical technologies in particular might in part produce rather than simply reflect such differentiation" (ibid: 8). The notion of "ontological choreography" is a helpful one to go beyond social constructivist arguments that presuppose one single object (subject) at the end of the imaginary road (see e.g. Bijker 1995). Here, technologies and selves keep shaping one another and the multiple realities of living with IVF technologies.

Thompson's analysis is influenced by and builds on another important concept that was coined to critique the homogeneity of social constructivism. *Enactment* has been developed by Annemarie Mol in her now widely cited study to designate the work of coordination between different realities of atherosclerosis in a Dutch hospital (Mol 2002a). Through detailed descriptions of the clashes and blending of narratives, facts, experiences and technologies around the clogging of arteries in one's leg, she insists that objects of disease—from faulty genes to anxious relatives to populations at risk—are accomplished in their relations to each other. The aim of such an ethnography is not to locate the idiosyncrasies of technoscience or their political and social consequences but to explore the constitutive ambiguity between scientific worlds, medical things and anthropological concepts.

The method of comparison is a case in point here. In health care, Mol suggests, establishing relations often takes the form of comparison, which



may be thought of as one specific mode of enactment. In the clinic, diagnostic values, painful legs and statistical differences of population become recognizable, tactile and worthy of knowing through the comparative practices of treating clogged arteries. Comparison, then, is not only a tool for the study of cultural and other differences, but a phenomenon that constitutes those differences (Mol 2002b). The multiplicity of objects, diseases for example, is not a matter of worldview and interpretations, but rather the practices in which things—medical things, among others—keep the contexts of knowing them open. In Mol's formulation, this approach is called praxiography, and as we shall see in Chapter 1, it has important connotations for understanding how differences are mobilized in at the sites of diabetes care (and anthropology) in Japan.

But before that, I will need to make explicit the politics of differences around disease and how they are entangled with and mediated through the very medical things—pills, genes, hospital wards, organs, populations—that are mobilized to deal with the multiplicity of facts and concerns.

## 5. Less than many: situating difference

*"To be clinically relevant, according to Feinstein, and experiment had to answer two kinds of questions: How are the patients in the study like my patients? How are they different?"*

— Harry Marks

That medical *things* articulate the body and its changing states of health and sickness in specific ways, suggests a multiplicity inside and around biomedicine that neither the unbounded diversity of subjective illness experiences, nor the notion of disease as a socially and culturally constructed,

homogeneous category can adequately capture. To challenge the epistemological assumptions of social constructivism without falling prey to the phenomenological blackbox of suffering, I will take a closer look at the multiple connections between human and nonhuman entities—which are made and remade in medical practices. Rather than a point of departure, the steps by which such posthuman diversity is built up are parts of the ongoing anthropological engagement with what Marilyn Strathern has called 'performative or critical multiplicity' (2015: 136).

In the burgeoning literature on the politics of things outlined above there has been a lot of discussion about the methodological problem of difference, multiplicity and alterity. Scholars of science, technology and medicine have gradually moved toward the view that concepts are intrinsic to artifacts, technologies, regulatory procedures and other material encounters in scientific and medical work (Bowker and Star 1999). In anthropology, on the other hand, the renewed interest in thingness often has been accompanied with a lateral mode of theorizing difference—whether latent or explicit (Boyer and Howe 2015). Turning things into conceptual tools forces anthropologists to treat theoretical concerns as ethnographic facts and vice versa by asking in what ways and for whom differences and similarities come to matter in scientific and medical practices (see e.g. Berg and Mol 1998; Choy 2011; Jensen and Rödje 2010; Kasuga 2011a; Mohácsi and Morita 2013; Yamashita and Fukushima 2005; Zhan 2009).

The work of Helen Verran provides a well-known illustration of this conceptual loop: the way anthropological theories and ethnographic objects come to mutually include each other in the process of understanding alterity as a creative response to empirical questions. In her book, *Science and an African Logic* (2001), Verran explores how different ways of counting coexist in

practice—that is in math classrooms in Nigeria. She tells us about ropes, rulers, cards, and also fingers and toes, among many other things used in these classes, to show how Yoruba and English numbers are translated into each other. Confronted with her first, relativist, take on the issue of indigenous mathematics, she has to ask herself a series of methodological questions about the nature of translation itself:

By privileging practices in numbering as I told of the generalizing logics, I saw myself avoiding the pitfalls of relativism, while arguing for possibilities of plurality. In my focus on practices, however, what I failed to recognize were my own practices, specifically practices of translation. Failing to notice the extent and nature of the translations involved in my relativist telling of the generalizing logic of Yoruba numbering thwarted my intention of discovering where the difference lay and how it was managed. (Verran 2001: 19).

What is at stake here is nothing less than the very concept of translation that transforms itself through the ethnographic tracing of slowly unfolding connections and differences around counting. As it turns out, then, the practical ontologies of counting and the myriad generative tensions it brings about point to a central problem of ethnographic description: how can we, again, take differences (and similarities) seriously?

In what she calls a performative account, Verran describes how number's singularity and the various versions of its objects emerge in and through the ethnographic setting. In doing so, she goes beyond a relativist telling of cultural difference and points toward the ontological effects of translation. As she notes, "the realities that numbers objectify are multiple, incomplete, infinitely partial, distributed, and potential. Reality is no longer completed, singular, and given" (ibid: 106–107). Having multiple ways of encountering numbers, this example suggests, it is the relations between such

encounters that generate creativity both in the classroom and in the conceptual work of anthropology. If ethnography is, indeed, a process of translation, it is a method that multiplies reality.

The methodological return to the problem of difference in much anthropological work during the past two decades has been built on the promise of providing an escape from postmodern relativism and identity politics. Advocates of the 'ontological turn' hope to replace cultural difference with ontological alterity (Carrithers et al. 2010; Holbraad and Pedersen 2017; Viveiros de Castro 2003). Paradoxically—but only at first sight—the claim that there is more than one reality entails the refusal of any easy pluralism. There are no different sides, or perspectives, from where to look at a singular natural sameness (e.g., disease); there are only sites where different versions of reality clash leading to what came to be called the ontological politics of multiplicity.

It is worth mentioning that these ideas have an affinity—an uneasy one, to say the least—with concepts of non-human living things in Japanese biological anthropology. Imanishi Kinji, the famous Japanese primatologist, for example, is mostly remembered for his insistence of non-human sociality among monkeys. And while his arguments have mostly been framed in the biological sciences, much of the impetus for his work came from the relative intimacy of monkeys and humans in Japan. In the first chapter of *The World of Living Things* (『生物の世界』) (2002 [1941]), he asserted that differentiation is inherent in the unfolding of the multiplicity of natural worlds. While these worlds are related in important ways, he noted, "humans have their own world, monkeys theirs, amoebae and plants each have their own world" (Imanishi 2002: 5).

But is this concern with difference and alterity as something more than human peculiar to anthropology?

Physicians, radiologists or epidemiologists work with and through all kinds of differences around disease, in a remarkably similar way to anthropologists. Ethnic variation is but one of them, as the following explanation of the risk of diabetes from a popular Japanese text illustrates:

Most Caucasian people's bodies can handle high-calorie diet by producing more insulin that turns food into fat. In contrast, when Japanese people follow a similar eating habit, their internal insulin secretion cannot respond adequately to such high-calorie diets. To put it simply, the excess food accumulates in their bloodstream in the form of sugar. If such energy-overconsumption continues for a long time, rather than putting on weight, they [Japanese people] will develop diabetes. The reason of Mongoloid people being at a higher risk of developing diabetes is a genetic factor that makes them more resistant to famine [as compared to Caucasians] (Yazawa Science Office 2003: 52; translated by the author).<sup>12</sup>

The *same* metabolic disorder, it seems, produces surprisingly *different* disease patterns and ethnic disjuncture when it comes to such mundane things as, for instance, eating. If most of us agreed that eating habits play a crucial part in how our bodies are more or less vulnerable to a certain disorder, we would be less comfortable with the idea that it is the disease itself that generates differentiation, including ethnic ones. But there seem to be too many obstacles in biomedicine and its anthropological studies when it comes to the issue of politics. As has been the case with old age in India (Cohen 1998) reproduction in the U.S. (Thompson 2005) or AIDS in Brazil (Biehl 2007), debates and policies around diabetes in Japan engage collective frames, such as race, gender or the nation. And while engaging with this kind of identity politics in medicine may open up a space for dialogue, it also

constrains the ethnographer to the pluralist vocabulary of the neoliberal state (de la Cadena 2010). There is seemingly no place for things in these political negotiations around identities in modern biomedicine. One has to return to the sites where technologies and devices are put into practice to reopen the question of difference,

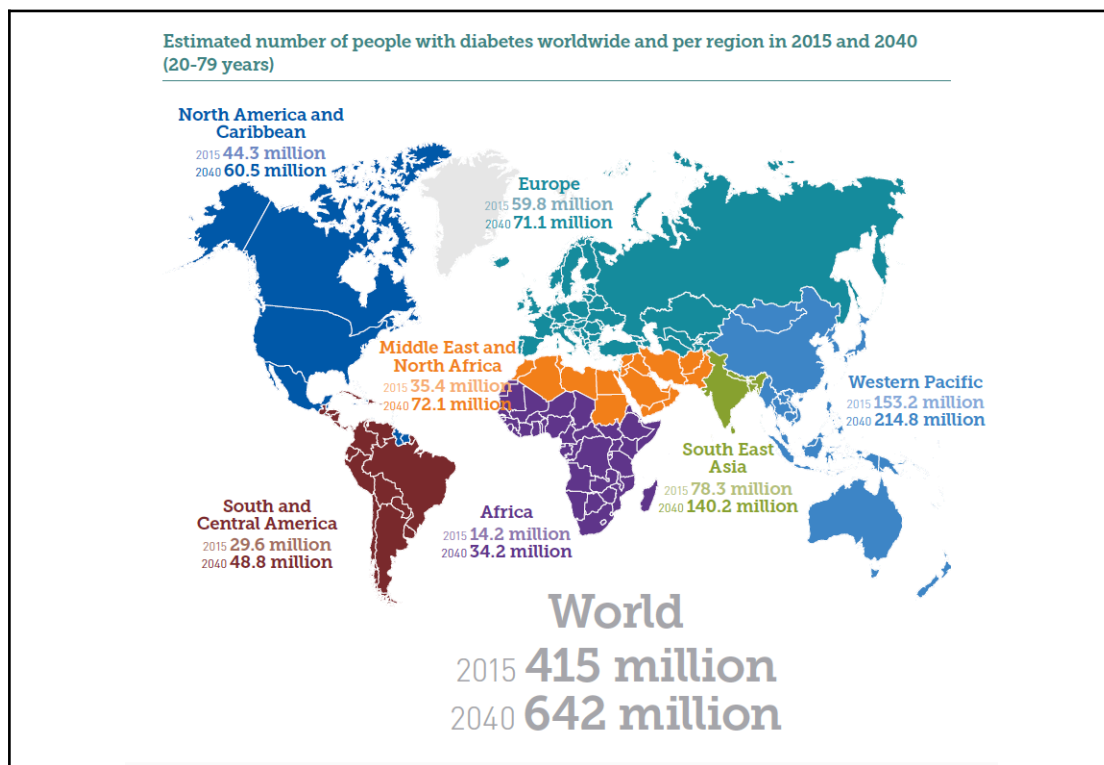
Thus, to start examining the multiplicity of diabetes in the making, what I needed was to stop taking them for granted (as social, cultural, material, etc.) and try to follow how they emerge at the clinic, clash in the meetings of patient groups, or taken up in trials of drug discovery *and* in anthropological accounts, for that matter. More than a static, outsider view to the diversity of medical knowledge and the experience of suffering, my interest lies in the mutual constitutions of social and biological differences. Instead of the ethnographic reification of cultural particularity, it is something broader and more sparse that I have in mind: to invent certain intersections that form and transform asymmetries between ontological orders and disciplinary divisions. Diabetes, as I will try to argue, has a critical role in such mediation between objects/technologies, subjectivities and the politics of life in contemporary Japan.

## **6. The (not quite) multiple worlds of diabetes**

This thesis is an ethnographic attempt to engage with the multiple worlds of diabetes as they emerge through unlikely technosocial assemblages of people, things, categories and bodies at clinical, research and everyday settings in Japan. At the first glance, this appears to be a bold venture given that diabetes, a chronic metabolic illness, has become one of the most common diseases around the world. Everyone seems to *know* these days what diabetes *is* and the assertion that it coexist in different worlds sounds bizarre, at the

least, and inappropriate for a scientific thesis at the most. The stakes are high.

From serious and less serious theories of sugar conspiracy to numbers that point to a global epidemic unfolding in front of our eyes to the mundane, almost unnoticed, perception of high glucose levels as a consequence of ageing, diabetes is now a major public health issue, as well as a daily experience of hundreds of millions of people. This suggests a common world rather than multiplicity. And while the name of the disease may reinforce this kind of unity, diabetes has been emerging in the last forty years through the very differences it entails. 'Difference' is far from a peculiar anthropological problem in the worlds of diabetes. It is the very ground of its existence.



**FIGURE Int-1 Mapping the plural world of diabetes**

Estimated number of people living with diabetes worldwide and per region in 2015 and 2040 (20–79 years); Source: *Diabetes Atlas*, 7th edition (International Diabetes Federation 2015: 17)

The 7th edition of the *Diabetes Atlas*—a biannual publication of the International Diabetes Federation—, for instance, starts with a map explaining the worldwide differences in the incidence of the disease (see *Figure Int-1*) and urges healthcare professionals for a regional perspective. The first chapter, following a definition of the condition<sup>13</sup>, explains that there are three main types of diabetes, adding that there are other, less common variations (International Diabetes Federation 2015:17; 22).<sup>14</sup>

Regional and etiological differences abound when it comes to diabetes as a public health issue. But anthropologists are weary. Here is what Steve Ferzacca, in his review of the anthropological research on diabetes, has to say about the different types of diabetes: "For type 2 diabetes, there are no microbes, viruses, organisms, or infectious agents, per se, involved in the onset and spread of the disease. In fact, *culture* and, now, *society* are the agreed upon vectors of the disease. (...) Culture is often cited as the difference maker, either as an etiological factor in the development of diabetes worldwide or as an explanation for diversity within the images, relations, and activities associated with diabetes." (Ferzacca 2012: 416, 421; emphasis added). We are basically back where I have started this *Introduction*. Diabetes, at least its chronic and most common variation, is a human affair and anthropologists should be focusing on the these cultural and social dimensions in their studies.<sup>15,16</sup>

In line with this, medical anthropologists have assigned themselves the roles and tasks of mapping the socio-cultural context of diabetes for more than three decades now roughly following the Malinowskian notion of acculturation (Fox et al. 2017; Malinowski 1944). Much of this work has been carried out in indigenous communities from North America to the Pacific, where incidence rates have been escalating. They reveal the clash between



specific ethnohistorical trajectories, traditional health concepts and the impact of colonization (Garro 1990; Lang 1989; Smith-Morris 2006). In other places, lay narratives and symbolic meanings have been repeatedly illuminated by medical anthropologists in the context of emerging public health challenges (Little et al. 2017; Naemiratch and Manderson 2007), migration and ethnic minorities (Borovoy and Hine 2008; Greenhalgh et al. 1998; Guell 2011; Mendenhall et al. 2010), changing gender roles (Iwasaki et al. 2005; Schoenberg et al. 1998), or community building in the face of social inequalities (Cabassa et al. 2008; Ferreira and Lang 2006). Others have further explored the different explanatory models by doctors and patients (Cohen et al. 1994; Hunt et al. 1998) or the dialogue between local communities and healthcare professionals (Montoya and Kent 2011). Japanese anthropologists working in Japanese sites have been following this dominant mode of inquiry into the narrative diversity of diabetes in this rapidly aging society. Ukigaya Sachiko's detailed ethnography is an account of the active embodiment of chronicity in Japanese diabetes care and the body's resistance to the hegemonic discourses of lifestyle disease (Ukigaya 2001; 2004). Hama Yūsuke, on the other hand, has used his own experience to provide an insight into the daily struggles of living with type 1 diabetes in contemporary Japan (Hama 2007).<sup>17</sup>

The list is too long to continue, but it should be sufficient to see how differences of diabetes have been framed in cultural anthropology as a problem of social suffering and cultural interpretation. Health beliefs and folk models, patients narratives and professional discourses are located in differences that map all too well to our familiar multicultural categories: gender, ethnicity, class, race, religion, profession. In these case studies the plurality of diabetes emerges through the narrative and interpretive layers of

shared or clashing meanings and perspectives, which is not so surprising given the fact that the method of interview dominates ethnographic research of this kind (Ferzacca 2012: 418).

In a sense, this tendency can be explained as the necessary self-assigned role of cultural anthropologists in the midst of the burgeoning studies rooted in classic four-field projects in collaboration with epidemiologists. Proponents of this latter approach have been taking a biocultural perspective, where the epidemic spread of diabetes, a "disease of civilization," we are told, and the different rates of its prevalence in different populations is the consequence of rapidly changing lifestyles that we are—biologically, evolutionarily, metabolically, etc.—unfit for (Eaton 1977; Okumiya et al. 2016; Ulijaszek et al. 2012).<sup>18</sup> Our bodies, it is argued, is genetically programmed for palaeolithic lifestyles of hunting and gathering.

The dialectical relationship through which these two genres have developed in and around the field of medical anthropology offer an implicit, if partial, insight into the place of difference and similarity in our discipline. While narrative accounts take it for granted that different people have different perspectives about the high levels of glucose in their bloodstream, biocultural approaches are grounded in the notion of a universal (natural?) human body of the hunter-gatherer. Human diversity, in both of these analytical frameworks, is mapped—quite literally (see *Figure Int-1*)—on biological sameness.

Complicating this dualism has been at the forefront of some recent anthropological and STS accounts of diabetes, and metabolic illness more generally (e.g. Solomon 2016; Yates-Doerr 2015). I will discuss two such trends that have been important in shaping the argument of this thesis: the anthropological interest in race and genetics and the problem of the patient-

as-user in diabetes care. Both of these thematic areas, interestingly, have to do with technological innovations that historically overlapped with my fieldwork. These studies have added layers of complexity to medical anthropological insights and will allow me to follow the shifting terrains of difference and similarities in diabetes care and research.

A topic of increasingly pressing significance since the early 2000s has been the emergence of molecular biology in diabetes research and the way it transforms former notions of race and ethnicity. Michael Montoya (2007; 2011), for instance, in his ethnography of genomic research into type 2 diabetes at the U.S.-Mexican border set out to challenge the assumption that race is either a social construction or a biological fact. "What happens," he asks the reader, "to the semiotic status of the materials (genes, blood samples, DNA donors) when they become the building block of a technoscientific enterprise? And, further, in what ways do these artifacts themselves inflect the social worlds out of which they were fashioned?" (2011: 9) Drawing upon the work of Annemarie Mol, he introduces the idea of mutual inclusion to demonstrate the confluences between genetic science and social inequalities through which "Mexicanness" is achieved and becomes a concern for both researchers and patients of diabetes.

Montoya's work may be read as a critical reappraisal of the geneticization argument in recent social scientific literature on diabetes (Hedgecoe 2002; Rock 2005a). Remarkably, such criticism of genetic determinism is not at all a purely theoretical concern of social and cultural anthropologists, but something that has been heavily debated in genetic medicine. These debates, in turn, overlap with anthropology in important ways. A more recent version of the biocultural approach, especially in physical anthropology, aligns itself with epigenetic findings to explain

diabetes as a result of the interaction between genetic and environmental factors (Kimura 2011; Kuzawa 2010; McElroy and Townsend 2014; Mulligan 2016).<sup>19</sup> The differences that are investigated in these studies develop in a much shorter periods than biocultural approaches have suggested. While former studies have been focusing on changes of lifestyle though tens of thousands of years, epigenetic research has moved the infant-mother relationship and fetal exposure to the spotlight. In the place of the plurality of populations without any direct link to their supposedly common hunter-gatherer ancestors has been replaced to a biological ground that is not only diverse, but inevitably related. As biological anthropologist Christopher Kuzawa has succinctly put it: "You are what your mother ate" (2013). The way epigenetics feeds into the anthropological critique of genetic determinism shows that theoretical concerns in one world are ethnographically traceable problems in another.

The problem of the user amid the rapid expansion of patient-centered technologies has been another issue that complicates the seemingly plural world of diabetes. People with chronic conditions use different devices that help them to monitor their disease. Diabetes is no exception—on the contrary. It has been a fertile ground for the innovation of so-called user centered technologies from self-monitoring glucose meters to iPhone applications that track daily calorie intake and other health data. STS scholars have been particularly attentive to these changes. (Mol 2008b), for example, has demonstrated how blood sugar monitors in the Netherlands articulate two profoundly different worlds of diabetes care: one of *care*, on the one hand, where they help cultivating attention to ones own and other bodies, and another of *choice*, where they foster autonomy and equality of the patient in the face of an all-encompassing clinical gaze. These two worlds are by no

means mutually exclusive: they hang together in the daily adjustment of glucose levels. Others have analyzed various encounters with diagnostic patient technologies, in which the boundaries between clinical and lay worlds have been reconfigured (Bruni and Rizzi 2013; Danholt 2013; Fukushima 2007), or the ways these technologies are constituted through comparison when they travel between the global North and South (á Rogvi et al. 2016).<sup>20</sup>

Diabetes self-care has become an important experimental space of what some have called Patient 2.0, "a human actor wired into a network of external health infrastructures and internal miniaturized devices, intermingled with institutions, organizations and social groups" (Danholt et al. 2013: 4). The diabetes patient, this argument goes, is now an agent producing data for other yet-to-be-patients being literally caught up in the ethical, political and legal discourses on difference and similarity (New Scientist 2015). As Judith Gregory and Geoffrey Bowker write in their analysis of the so-called Quantified Self Movement: "As we live more and more algorithmically through self-tracking, our identities are necessarily being caught up in the cloud" (2016: 211). People who suffer from various sorts of complications known to be the consequence of living with high levels of sugar in the blood for a long period time, as well as the wide range of pharmaceuticals that are approved on the basis of their scientifically proven difference from other medication on the market—to name just two of the most obvious sets of differences in diabetes care—are all parts and parcels of these identities caught up in the cloud. Or, rather clouds: digital, conceptual, personal. It is at the intersections of these differences where the multiple worlds of diabetes, the object of this study, become matters of concern.

Rather than a set of mutually exclusive differences, the multiple worlds of diabetes come into being with the nonhuman entities that are interwoven

into and embodied through the technoscientific routines of knowing it. It follows from this that differences and similarities, rather than being the starting point for anthropological questions, are matters of concern for those—patients, physicians, nurses, families, politicians, engineers, etc.—who have to deal with them on a daily basis. These everyday routines of differentiation provide an entry into what I call, after Giovanni da Col and David Graeber (2011), an ethnographic theory of disease. Rather than considering disease as *a text to be read* (listened to, interpreted, etc.), this thesis will take a different take to demonstrate that disease, although it defies any clear meaning most of the time (see Cohen 1998), nevertheless enables the ethnographer to *do theory*.

## 7. The field

If differentiation is an ongoing process of living with diabetes, where exactly should its anthropological study start from? Differences, after all, are everywhere and they disaggregate in many different directions. And so, too, do ethnographic fieldworks. Contrary to remote islands and hill tribes waiting to be discovered by the once-upon-a-time anthropologist, the field sites of diabetes in Japan are replete with knowledge of a non-anthropological kind: facts, numbers, theories are themselves the field to be entered. Should I start then with the obvious facts and numbers? As I will try to show later, numbers and facts are anything but obvious. It maybe for this reason that they can tell a lot about the trajectory of fieldwork in sites that are filled with them. Diabetes is a case in point.

Few diseases have pervaded the landscape of Japanese health care in the past fifty years as thoroughly as diabetes (*tōnyōbyō*). It has transformed itself from an obscure and acute condition to one of the paradigmatic issues of modern biomedicine. The prevalence of diabetes, specifically its non-insulin-

dependent form (type 2), has been increasing rapidly during the past two decades, making it the most common lifestyle-related disease (*seikatsu shūkan byō*) in one of the world's most aging-anxious societies. More than 5 million people are estimated to be directly affected by high blood sugar levels that, along with the complications of diabetes, lead to a significant decline in what epidemiologists call the quality of life (QoL).<sup>21</sup> According to a survey conducted by the Ministry of Health, Labor and Welfare in 2012, the number of diabetics in the Japanese population above 20 was estimated at 9.5 million (men 15.2%; women 8.7%) totaling over 20.6 million when prediabetics (*tōnyōbyō yobigun*)—those with impaired glucose tolerance—were included (men 27.3%; women 21.8%).<sup>22</sup> The growing number of patients and the load on their families (and the state) have drawn much attention in the popular media to the daily routines and bodily awareness associated with chronically high blood glucose levels. In general, diabetes is becoming one of the major challenges of political interventions in health care and epidemiology of the twenty-first century, often referred to as a "national disease" (*kokumin byō*)<sup>23</sup>—a term that was used for tuberculosis during the first half of the 20<sup>th</sup> century. Its public health implications grow along with the potential market of newer and simpler medications, making it one of the most dynamic fields of collaboration among the state, scientific research, and private drug companies.<sup>24</sup>

It is far from obvious how this profusion of stakes, sufferings, things, and people can be studied in their multiplicity without reducing them into one single problem. Anthropologists interested in the ever fluid nature of identities, may advise you that to conduct your fieldwork multi-sited following information, the flow of people, things and ideas, and the problems accompanying them. Or, on the contrary, they invite you to a new dimension

of ethnographic reality in front of TV or computer screens chasing digital circuits in the cyberspace or just watching the Olympic Games where cultural, social and gender differences clash and identities are performed in an intensive mode of self presentation and value production. If differences are everywhere, it follows that ethnography too has to be, well, everywhere. But that of course, is impossible. Ethnographic studies have to come to a closure. This makes them remarkably different from chronic diseases.

A strong alternative to multisided ethnographies has been the trend of laboratory studies, in which such closures are solved topologically (see e.g. Latour and Woolgar 1979; Myers 2015; Suzuki 2017). Many sociologists studying practices of science and technology in the late seventies and early eighties have been eager to follow Bruno Latour and his colleagues into the laboratory arguing that it is not so much different from a village in Melanesia or England. Latour, who has been trained as an anthropologist—but failed as a fieldworker in the original (romantic?) sense of the word—, is quite explicit about this analogy in one of the philosophical digests of his views, *We Have Never Been Modern* (1993). In a nutshell, he tells us that the world *is* in the laboratory and scientists are its savages. An anthropological analysis of that world would require one to stay in the laboratory with scientists to understand how the world is being constructed. There are at least two obvious problems with this approach that I want to mention here. First, scientists very rarely stay in the laboratory these days. In the medical sciences, for instance, as I will explain in Chapter 5, they come and go between the clinic and the laboratory; and between conferences, medical manufacturers, and Kasumigaseki—the administrative district in Tokyo and the center of Japanese political life. They also spend a significant amount of time with their families and friends who may be other scientists, so the world of disease and



its technoscientific mediation cannot be reduced to the laboratory. Scientists, not quite surprisingly, get sick sometimes, and this leads to the second problem with the methodology of early laboratory studies.<sup>25</sup> That the world we live in—of disease, for example—is not a pure scientific reality even in its medical enactments. And while embodiment may often be the very context of scientific knowledge making (Kuriyama 1999; Lawrence and Shapin 1998; Polanyi 1966), at other times it is source of pain, suffering or spiritual ecstasy (Desjarlais 2003; Duden 1991). Taking the laboratory as the place of origin for the many kinds of differentiations in and around chronic metabolic illness is just as misleading as taking, say, the body as the bottom end of experiencing and living with disease.

To find our way between the virtually endless sites of diabetes and the laboratory as its place of origin, I need to underline once more what has been stated above: throughout the three years of fieldwork that forms the basis of this thesis, I have been committed to leave the question of difference open. This had important ethnographic consequences. As anthropologist Matei Candea—building upon the work of Eduardo (Viveiros de Castro 2003)—notes in the Introduction of his book *Corsican Fragments* (2010), by refusing to take any sort of difference for granted, the anthropological analysis must always remain *in medias res* aligned with its ethnographic material. The field site in such a methodological setting is, what Candea calls, an "arbitrary location." Contrary both to the abstract notion of the Weberian ideal type and to the reconfiguration of holism in multisided ethnographies,

(...) the arbitrary location (...) is the actually existing instance, whose messiness, contingency, and lack of an overarching coherence or meaning serve as a control for a broader abstract object of study. It is arbitrary insofar as it bears no necessary relation to the wider object of study (Nuerland to politics, the

Troband islands to the Oedipus complex). While the ideal type allows one to connect and compare separate instances, the arbitrary location allows one to reflect on and rethink conceptual entities, to challenge their coherence and their totalizing aspirations. (Candea 2010: 34)

In sum, the notion of arbitrary location brings into view not only the plasticity and contingency of the ethnographic field site, but also the puzzling ways our concepts are both embedded and made from the places that we call the 'field'.

In a similar fashion, entering the field site(s) of this study, as I will discuss in Chapter 1 in more detail, was a progressive loop of theoretical and empirical steps towards what I have described above as the ethnographic theory of disease. It follows from this that, unlike more conventional doctoral theses in anthropology, this one is not really a study *about* Japan. Nor is it quite an anthropology *of* biomedicine. The arbitrary location of this research is rather diabetes itself. That, of course, is not to say that it started from nowhere. It actually started at one of the peripheries of what has been called 'Japanese culture,' more than an hour drive away from the nearest hospital.

**CENTRAL HOKKAIDO, 2000**—When I first traveled to Japan in the late 1990s to study the language my aim was to study inequalities as a consequence of depopulation in rural Japan. The island of Hokkaido seemed to be the perfect place for this due to its relatively short colonial history. And so it wasn't long before I found myself doing fieldwork in a small mushroom-growing village in Central Hokkaido. At the dinner table, my host, a mushroom farmer, and his wife were discussing a pamphlet that was delivered by an agent of a life insurance company earlier that day. The introductory paragraph was explaining to the reader the financial costs of "growing old in the world's most ageing society." But the couple was more

interested in the part that explained the conditions for enrollment. "It says you need to have a medical check-up before signing the contract," the wife said. "What for?" asked Miyata-san, the husband, turning his head away from the baseball game in the TV, for a moment, toward the document on the table. "I'm not sick, or anything," he replied his own question. In the bottom line of the pamphlet a text printed in small fronts listed some of the major excluding factors: "high blood-glucose levels, hypertension, asthma" etc. The character for disease (*byō*) was quite noticeably missing from all these words. There was no disease, but there was a fine line between those who had a quantifiable risk of developing it later and those who haven't. The fine line was drawn neither through discourse, nor in a narrative, but in series of thorough medical examinations called *ningen dokku* in Japanese.

And while a health check-up did not seem to be the most interesting place for my project on rural depopulation, I nevertheless decided to accompany Miyata-san, as I did not have anything else to do for that day. At the hospital, the waiting room was filled with single men being educated about the dangers of chronic diseases and the importance of balanced nutrition with a more or less clear message that living a married life and preventing these conditions have much more to do with one another than they had previously imagined. The idea of living a bedridden life without a supporting family was anything but appealing to these middle-aged men. I remember arriving at home that evening packed with healthy recipes and all kinds of pamphlets about diabetes and other kinds of lifestyle diseases. Miyata-san, however, had other things in mind. He was discussing the possible effects of *enoki* mushroom on high blood sugar with his wife and how that could be used in the advertisement of their produce. In the course of a single day, along with diabetes I traveled from life insurance regulations to

the precarious future of men in rural Japan to family and kinship values and mushroom that may help in the future. As I found out later, however, the multiple world of diabetes in Japan was, in many ways, even more mundane than this first encounter might suggested.

While finishing my project on depopulation, I made the decision to conduct the research for this thesis in two different locales and many more field sites. One of them, the city of Sapporo on the island of Hokkaido, is in many sense a frontier of Japanese medicine—or, more generally, science and technology—and an experimental site where many novel technologies, including medical and pharmaceutical ones, are first introduced (see e.g. Hansen 2014; Swanson 2015). Tokyo, on the other hand, is one of the major hubs of global medical research and, at the same time, an urban space where the entanglements of chronic disease and the impact of an ageing society are intensely local.

Following short pilot studies in both cities, the main fieldwork for this theses stretched over a period of three years between 2003 and 2006, and extended into several post-fieldwork activities with patients and activists I met during these years. I have adopted a five-pronged approach: (1) long term participant observation in two sites, (2) shorter visits to clinical and other facilities, (3) attending conferences and exhibitions, (4) in-depth interviewing of patients and experts and (5) engaging with the latest popular and scientific literature on diabetes.

First, and foremost, I conducted *intensive long term participant observation* in a diabetes clinic in Sapporo (8 months) and in a small patient advocacy group in Tokyo (18 months). My work in both places entailed following patients and medical experts in their daily work and activity of treatment and prevention. In the hospital, I observed more than a hundred medical visits,

two surgical operations and more than forty diagnostic tests, including ultrasound, CT and ophthalmoscopy (examination of the eye). I participated at the weekly staff meetings (where I was not allowed to take notes), the daily diabetes classes and the training sessions for self-monitoring and insulin administration. I spent three days helping the pharmacist (*yakuzaishi*) to prepare the medications in her office and followed two different social workers in their daily visits. However, the most productive time of my fieldwork in the hospital have been those seemingly endless hours that I spend in the waiting room of the outpatient clinic, the cafeteria and the dialysis unit, where I could be part of the slow unfolding of these metabolic encounters. My work with the patients group was less intensive allowing me more time to discover Sunamachi, the neighborhood in Tokyo where the members of the group were living. I attended the monthly meetings of the group, helped to organize events such as preparing meals together, inviting medical experts and weekend trips to hot spring resorts. I also collected information on diabetes advocacy from around the world and gave a seminar at one of the monthly meetings and participated in the edition of a publications about living with diabetes.

To enhance these findings, I made *shorter visits* to small clinics in Tokyo, a university laboratory, various public health facilities and two pharmaceutical manufacturers that allowed me a deeper insight into the scientific, technological and political work of treating and preventing diabetes (1-2 day visits per site). In addition, I *attended* scientific meetings and pharmaceutical exhibitions as *ritual sites* of innovation and promotion. And while the methodological aim of this study is to overcome the narrative limits of much of the medical anthropology literature, I also examined the practices of living with diabetes through *in-depth interviewing* of patients in their homes

or in hospitals, physicians at clinics, and endocrinologists, epidemiologists, genetic researchers and other medical experts in various institutional settings. Rather than their hermeneutic devices, I consider these talks as parts of the daily practices of living with diabetes.

At last, but not least, all of these different approaches have been embedded in an ongoing engagement with the issue of lifestyle diseases in Japan through *the media, popular and scientific literature* of the period of the research. During these years, technological innovations—human insulin, pancreas transplant, wearable technologies, etc.—and their rapid diffusion have considerably transformed the stakes in diabetic compliance. Also, techniques of prevention and lifestyle changes associated with high blood sugar levels have extended into far into the lives of many Japanese people. These transformations show how the multiple, intersecting realms of scientific theories, technical devices, potential profits, clinician-researchers and patient advocacy groups have as much to do with the forms that living with diabetes take as the metabolic aspects of the disorder or patients' experiences of their bodies.

## **8. The chapters**

It would be hard to find two ideas more antagonistic than those that underlie contemporary biomedicine and anthropology. The former is based on the notion of the universal human on which scientific evidence and chemical effects work alike from university hospital wards in central Tokyo to the health aid posts in the Yanomamö village of Mavaca deep in the Amazonian rainforest. Anthropology, on the other hand, is the science of human variation, as students are being told from the first day of the Introduction to Cultural

Anthropology class. No wonder that most of the medical anthropological corpus is a loud critique of Western medicine and that the few medical experts who show some interest in this field are harsh critics of their colleagues (Eguchi et al. 2006; Fassin 2017; Healy 2012).

This thesis will consider disease from a different position that resists such antagonism between anthropology and the biomedical sciences. As my argument develops, I will try to bring these two group of disciplines into a productive *relationship* by employing some concepts and methods from the social studies of science and technology (STS). My aim, in short, is to reexamine the notion of difference in anthropology through the lens of disease, especially as it is employed in clinical and biomedical knowledge practices.

The thesis is divided into two parts and seven chapters (not including this Introduction, which is soon coming to an end). Through an ethnographic engagement with the technosocial situations of diabetes care in Japan, I follow two ways in which the metabolism is acted upon: learning (Part I) and comparing (Part II).

The key element of Part I is the appropriation of simple medical technologies by patients and the multiple frames of differentiation that emerge from the clash of technological manipulations of and on the human body in an open-ended process of learning: emplacing, encountering and embodying metabolic differences.

Chapter 1 follows the *emplacement* of diabetes care through four entries into the place of disease. In most anthropological studies, a common-sense understanding of "place" is the physical location where the people being studied actually live (work, eat, have families, wage wars, etc.). In order to start developing a more dynamic notion of what I called "the ethnographic

theory of disease," I will need to turn around this static notion of place and show the emerging and generative side of how disease actually "takes place". To do so, I will follow four different routes of entry to the place of disease: a conceptual, a historical, an ethnographic, and finally the patient's route. Chronic disease, here follows the materially and bodily mediated arrays of collective knowledge practices. It is neither simply a momentum for cultural meaning making, nor just a settled matter of taken-for-granted scientific facts.

To investigate this matter further, Chapter 2 focuses on two essential steps in the organization of diabetes treatment at the hospital: eating and diagnosing complications. As I will show, the particular disorder and the risk of complication of any one person with diabetes is revealed, understood and diagnosed through the meticulous process of his or her acquiring of the general ideas and specific skills of living with such a disease. I will discuss the infrastructural routines of confronting "subjective" feelings (in patients) and "objective" findings (in laboratories) and their interaction in the daily *encountering* with metabolic disorder.

Chapter 3 takes up the issue of *embodiment*. I will show the different ways of objectifying and appreciating the symptoms of diabetes by doctors, patients, devices, bodies and user-consumers of medicine in general. To locate the power of such symptoms, I trace the emergence of disease through three different procedures of managing diabetes: measuring blood glucose levels, detecting diabetic complications on CT scans and slides of blood viscosity, and, finally, the interweaving levels of choosing among a wide range of available medications. In addition, I describe how diabetes travels to the home of patients with mundane technologies, such as pills, pictures and measuring kits that literally "put" scientific values on affective bodies, as the Japanese *mi ni tsukeru* beautifully captures.



In Part II, I will approach diabetes as a comparative entanglement between state-of-the-art science and public health intervention on a massive scale. Different facts and experiences that structure the knowledge about diabetes emerge here within particular interferences between scientific and cultural attributions.

Chapter 4 explores how embodied knowledges are being apprehended in the science of diabetes, especially in epidemiology. In the past two decades, the powerful administrative trends toward standardization and the homogenizing forces of evidence-based medicine were intended to clear away the messiness of medical research in Japan too, but along the way they created new interferences between scientific and cultural claims of differentiation. This is perhaps nowhere more evident than in the burgeoning of clinical trials for diabetes. Here I argue that clinical trials are important sites for thinking about how differences come to the fore in the production of scientific knowledge. The social perception of the distinction between "working men" and "housewives" and the physiological differences between Asian and Japanese bodies, as I try to show in this chapter, *include* one another in the daily practices of clinical science.

The story of adiponectin research, as told in Chapter 5, will allow me to explore further how these two trajectories of differentiation come to stand for each other in the collaborative arrangements between laboratory, clinical and regulatory activities. How does the body of the diabetic patient become an experimental site of biotechnological and public health innovations in contemporary Japan? What is at stake when these bodies move across different locations and scales in the comparative practices of pharmacogenomics? These are the questions I pursue through an ethnographic presentation of adiponectin, a fat-cell-derived hormone—

involved in food intake and glucose metabolism—that has attracted considerable attention in the early 2000s in the study of diabetes. By exploring three planes of the adiponectin research (genetics, epidemiology, and drug discovery), the analysis of this case study suggests that genes and populations, publics and scientists, cardiovascular disease and diabetes are not static objects of medicine but rather *interfere* with each other in their differences through a series of comparative practices, such as linkage analysis, haplotyping, or clinical trials. In addition, this chapter is also an attempt to bring the notion of "local biologies" to bear on thinking about molecular, environmental and ethnic variables as they interfere in the quest for producing credible scientific evidence of the genetic risk of diabetes.

Chapter 6 revisits the world of patients and continues to explore the embodied mediation of the multiplicity of diabetes. Here, I focus on the activities of a patients' advocacy group in Eastern Tokyo. Their claim of collective identity around the shared experience of chronic illness reveals a dynamics whereby living with diabetes keeps connecting and splitting personal and political realms. The question here is how and why these two radically different horizons of diabetes are aligned (or not) in the emergence of new biosocial communities who now increasingly intervene into the treatment and prevention of chronic disease. The immediate aim of this chapter is to shed some light on the changing nature of lay intervention in medical care, and, more specifically, the mobilization of communities in health promotion and disease prevention. In so doing, I will consider the work of translation in which the knowledge of blood sugar as provided to us by modern medicine and the subjective forms of human suffering come to posit each other in hybrid events such as the comparison of flavors and calorie intakes in the self-help group and the marketing of health products, in

more general. I will call such situations technosocial *commensuration* in order to indicate the complexity of comparative practices in contemporary healthcare.

In the final chapter, I return to the question set out at the beginning of this Introduction: how do biomedical technologies and innovations force us to rethink the fundamental anthropological problem of difference? After drawing together and building on the main themes of learning and comparison explored throughout the thesis, I will propose the notion of *metabolic togetherness* as a mode to extend the ethnographic method beyond the notion of pluralism and diversity in a move that requires the anthropologist to take ethnographic theory seriously.

Writing an anthropology *in* medicine does not promise that there is something to be said about either medicine or anthropology as a whole. It suggest that there may be important findings in medical practice that correlate with other anthropological findings situated in other localities (of region, expertise, etc.); or, from another dimension, that ethnographic theory has something to tell that may be of interest in the contexts of encountering modern medicine—that is to say for nearly all of us.

# **PART I**

## **LEARNING DISEASE**



## CHAPTER ONE

### **The Place of Disease**

*in which disease enters the anthropological stage in the form of local practices*

Diabetes is a complex disease. For one thing, writing an ethnography of it requires one to engage with an anthropology *in* medicine. To be sure, such an endeavor does not promise that there is something to be said about either medicine or anthropology as a whole. It suggests, instead, that there may be important findings in medical practice that correlate with other anthropological findings situated in other localities (of region, expertise, etc.); or, from another angle, that anthropological theory has something to tell that may be of interest in the contexts of encountering modern medicine—that is to say for nearly all of us. For the anthropologist, this also begs the methodological question: is it possible to portray diabetes in an ethnographic way? And if it is, *where*, of the many possible places, one should look for it?

#### **1. Meanings, knowledges, practices**

The assumption that chronic conditions mobilize persons and societies to make sense of the world constitutes the anthropological topos of illness (Ikeda and Okuno 2007; Kirmayer 1992; Kleinman 1988; Young 1982). At the source of such accounts is the ethnographer's supposition that cultural *meanings* are endless and singular and that they are prior to the more general and less differentiated *knowledge* of biomedicine.<sup>26</sup> The ethnographic question, however, is: how are these meanings and knowledges connected? There are

conditions that make sense for the doctor but not for the patient (and, of course, the other way around); pharmaceutical salesmen and health policy makers have yet different perspectives and ideas on disease and health. Language and communication do not always offer an easy link.<sup>27</sup> And yet, such understandings are not inexorably fragmented as long as there is something to be treated. Instead of an infinite plurality of interpretations and meanings, the experience of disease feeds into human interactions and the material realities, not least of the bodies being ill, that are made and remade in a variety of (but not endless!) practices.

Chronic disease, as I will elaborate below, follows the materially and bodily mediated arrays of collective knowledge practices. It is neither simply a momentum for cultural meaning making, nor just a settled matter of taken-for-granted scientific facts. What is more, not only are the two not mutually exclusive, they are deeply intertwined with one another. So, what if instead of unwrapping embedded practices of a seemingly coherent medical knowledge, we presume such knowledge as the practice itself? What if we stop saying that knowledge is constructed in scientific or medical practices (Collins and Pinch 2005; Latour and Woolgar 1979), and we propose instead that medicine is a *practice of knowing*?<sup>28</sup>

This will require a methodological shift in the mode of analysis. In most anthropological studies, a common-sense understanding of "place" is the physical location where the people being studied actually live (work, eat, have families, wage wars, etc.). In order to start developing a more dynamic notion of what I called "the ethnographic theory of disease," I will need to turn around this static notion of place and show the emerging and generative side of how disease actually "takes place" (Candea 2010: 5). To do so, I will follow four different routes of entry to the place of disease: one conceptual,

one historical, one ethnographic, and finally the patient's route.

## **2. *Purakutisu*: places of theory**

### *Practical diabetes*

To be sure, starting from objects and practices is not at all an anthropological idea. It is what nurses told me at the diabetes center in Sapporo showing a long checklist of all kinds of daily routines patients had to remember before they were discharged. It is what doctors explained to people coming for their monthly dose of insulin or pills at small outpatient clinics in downtown Tokyo. Also, and not incidentally, it is what leading endocrinologists write in journals of diabetes care. One of them, published by the Japanese Diabetes Association even goes under the title: "*Purakutisu* (Practice: Journal of Practical Diabetes)!"

Most of the articles in it insist upon the multiple passages between expert knowledge and personal experience: innovations in genetic research appear next to the recruitments for clinical trials; congress reports are accompanied by columns of local patient organizations nationwide. Experts suggest that it is not they who know about diabetes, but those who suffer from and try to deal with it in their everyday life. The 'newest drugs' section is followed by individual stories of 'self-care', mostly about diet and exercise. Self-treatment becomes a forced invitation to act in one's own terms and to attend the disease deep inside one's body. Such management of the disease is, in turn, assumed to allow professionals to further map the biology of glucose metabolism. Disease, here, is not taken as a point of departure nor as an end in itself, rather it is presented as a sequence of knowing. Diabetes emerges as a part of the practices in which it is being encountered, shared by patients,



doctors, nurses, researchers and eventually all "Japanese people"—at the ever increasing risk of diabetes. Many of them, as we are frequently reported in a special column, visit famous overseas clinics in groups and bring home the newest treatment techniques of international diabetes care.

Each of the columns foregrounds how disease is done, and how the suffering from diabetes and the scientific knowledge of it hang together in the continuing management of high sugar levels in the blood. One might expect to find such managed and controlled selves as determined by biological notions of the pathological and the normal, and discourses about a healthy society of responsible citizens (Canguilhem 1989 [1943]). The articles in *Purakutisu*, however, reveal a somewhat different picture. The knowledge of disease is from the beginning—if there is one, indeed—incorporated in the acts of knowing it.

Here's one example to illustrate the point. Effective treatment of diabetes, a report says, requires medical professionals to appreciate disease with their bodies (*karada de oboeru*). Rather than asking "what we know about diabetes?," the nurses and other diabetes specialists at this meeting reported about "what they felt" after climbing up to the fourth floor of a building instead of using an elevator; or drinking three cans of beer after dinner. They, then, converted all these events and sensory data to a table with categories like 'objective measures', 'empowerment', 'comparative training,' etc. in a hope to learn something about how such *feelings* translate into blood glucose levels and how they could be a target of intervention (Yoshida 2003). In this report, diabetes is not an object of pathology, nor an expression of suffering. It is rather a dialectical relation between the two. In practice, treating and diagnosing, experience and knowledge intersect in many different ways, and at many different sites: at clinics, on bodies, in families. Sometimes even in

professional magazines.

### *Anthropological understandings*

This appeal to the practical understanding of disease resonates with another field of study situated fairly distant from endocrinology on the Japanese scientific landscape: that of the anthropological study of practices (*purakutisu ron*).<sup>29</sup> Not unlike in the journal mentioned above, here again *purakutisu* is used in the original English form when schemes of action in religion or work are examined. The reason for this—which may come as a surprise to those familiar with classic debates of self and group in Japan—is that the native term for practice, *jissen*, is said to connote individual behavior (Tanabe 2003). Contrary to this, the anthropological idea of *purakutisu* indicates that it is through the participation in collective events that individuals become both subjects as well as objects of social cosmologies, the classic examples being shamanistic rituals and other religious events.<sup>30</sup>

This is how Tanaka Masakazu tries to get away from the idea of fixed and given identities. Building on his own investigations of death rituals in South India and Sri Lanka he shows how in such religious activities individual and group identities are constituted and performed in a constant dialogue through time. Animal sacrifices or the ritual burning of widows, he claims, are more than expressions of values or representations of cosmologies. In and through each embodied act of the ritual, the personal and social experience of religion become intertwined. It is, in Tanaka's view, through the participation in such practices that allows both the performance of and the resistance to durable social structures, including that of power relations, in a given community (Tanaka 1997; Tanaka 2002).

Cultural fixities and orders of things, theorists of *purakutisu* say, are

constantly mediated in an open-ended process of learning about and accounting for the local worlds people engage with. Moreover, such observations may be extended from small communities to the complex organizations of modern societies. In his comparative studies of contemporary workplaces, Fukushima Masato (2001; 2010), influenced by Marxist histories of technology, foregrounds the problem of routine by stressing structural and historical factors. At the same time, he argues that the importance of locally acquired, specific techniques and tacit knowledges lies in the implicit processes of learning and a tendency of being usually left unaccounted (2001: 148). The locales (*genba*) introduced in these works are rather unusual places of learning: a nurse station in a psychiatry unit or a petrochemical complex, for example. What is common to all these places, Fukushima tells, is that the work done there and the embodied ways of learning and organizing of such work are always mutually inclusive. The skills of doing a job and the processes of acquiring them overlap in time and space.<sup>31</sup>

It is not at all obvious where we (and *others*, of course!) draw the line between knowing of and living in the world; between believing in gods and seeking expiation for sins; or between the scientific knowledge of the chemistry of ethylene and the daily routines of labor in a petroleum factory. These are all practical matters, as experts of diabetes care are well aware. The anthropologist's parallel proposition is something like this: what if we abandon the idea that gods and chemical reactions are *out there* in the form of mental schemes, and instead admit that they are very much a part of our everyday practices? As Tanabe Shigeharu powerfully argues, knowledge, by nature, is incorporated in such daily events:

(...) the emphasis is on how knowledge is situated inside practices. (...) Knowledge is not written in books. It resides in the lived reality of the body. (...) I will call such immanent ways of knowing: 'practical knowledge'. Such 'practical knowledge' operates in all possible walks of everyday life. That is, we do not determine what is known, rather we are *living through knowledge*.<sup>32</sup> (Tanabe 2003; translated by the author; emphasis added)

My concern below, however, is neither labor processes nor ritual performativity, but something fleshier: disease.<sup>33</sup>

The diabetes clinic is a place where medical knowledge about and self-awareness of the body come to be aligned. How are these new ways of knowing embedded and embodied in the daily encounters with disease? Interestingly, what specialists of diabetes care propose is very close to the anthropological idea of *purakutisu*: making sense is a practical matter, a matter of how disease is done. And yet, it is also different. The body, this time, is not merely a link between individual, group and society. It is something that hurts and gets old too. Doing disease implies that knowing the body in a scientific manner and inhabiting it in the phenomenological sense hang together; it means that establishing biological facts of the normal and the pathological and that living with them are interdependent. They generate and substantiate each other starting from the clinical settings of medical practice.

### **3. The Suzuran Diabetes Center**

Diabetes hospitals are instructive places to look for the co-production of scientific facts and human values, the interdependence of physical distress and organizational infrastructures, although such complexity is rarely developed into a *modus operandi* for treatment. The Suzuran Hospital, a center for diabetes care in the city of Sapporo (Hokkaido prefecture) is an exception

that proves this rule. Importantly for the following discussion, the constitution of a space where these different domains of disease are *not* disentangled was implicit in the establishment of the center some twenty years before my arrival.

*From family hospital to diabetes clinic*

This institution, the ethnographic focus of the first part of this thesis, is an outgrowth of slow but steady healthcare reforms in Japan during the 1980s and 1990s, the aims of which were to reduce the burden of elderly care on three different levels: first, and most generally, in terms of a new social policy of community based long-term care; second, in the form of financial measures to cope with growing health expenses of the state; and third, through a rationalization of medical service, namely the limitation of terminal care for old people in general hospitals by offering insurance-covered home-helper services and by increasing the number of long term care facilities.<sup>34</sup> The very same reforms, on the other hand, created new pressures for private hospitals to reduce the average length of stays as a measure to avoid being designated a "hospital for the elderly" (*rōjin byōin*). One potential to do so was found in the strategy of specialization. Health care institutions designated to the treatment of lifestyle diseases and chronic conditions have begun to proliferate in regional hubs all over Japan since the 1980s, and the founders of Suzuran Center had similar ideas and hopes about the prospects for diabetes in Hokkaido—the northernmost of Japan's four main islands.<sup>35</sup>

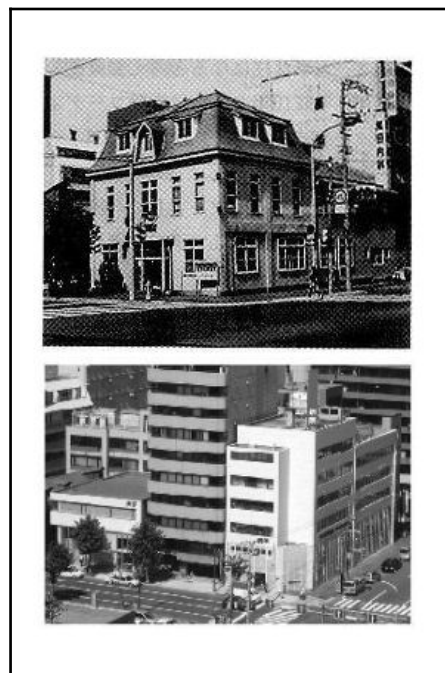
Most of the staff had previously been employed in university hospitals and public health institutions, and were critical of what they considered professional ignorance of the complexity of diabetes. As Dr. Komata, an endocrinologist with years of experience in American research institutes,

declared in an interview, the mediocre status of diabetes in Japanese hospitals was a strong emotional motive for his decision to accept the invitation of Suzuran's director: [At the university] "nobody had an idea that we were treating the same disease. Nurses would collect blood all day long for all kinds of symptoms. Technicians would take X-rays of literally any part of the body without much of a clue of what they were looking for. Some patients on dialysis couldn't adjust their schedule to the monthly check-ups, and others just skipped the ophthalmology examination, because no one took the time to explain them about the danger of eye disease in diabetes. It would take ages to reach a fairly comprehensive diagnosis, and even then, it wasn't certain that we could follow up with therapy. Patients were abandoning treatment because of the long waiting hours, while others were hospitalized for ages without any serious problem whatsoever. You probably won't believe me, but I saw old people occupying beds for years, because there wasn't a relative or a friend who could inject insulin for her three times a day...Every day I was dreaming of a place where I could treat *disease*, not doing elderly care."<sup>36</sup> Suzuran Hospital seemed to be just the perfect place for Dr. Komata.

The director of the center, Dr. Mihara, was a man of vision. He had transformed the family hospital into a large and well-equipped medical complex. His father had established a good reputation as an internist by founding a private clinic in the middle of the city during the economic boom of the sixties. But when Dr. Mihara—who first specialized in gastroenterology to follow his father—took over the hospital in 1982, he decided to set up a center for diabetes care. He spent five years in a diabetes ward of a university hospital, which provided him with solid basis: expertise in endocrinology, a personal network of experts (as well as patients), and frustrating memories of the chaotic state of treating chronic conditions in general hospitals (*sōgō*

*byōin*).

Dr. Mihara has come to see the state of diabetes care as a failure to account for the heterogeneity of the disease. So, what was at stake was how the manifold and complex mechanism of glucose metabolism could serve as an organizational blueprint of a modern hospital. It involved two necessary steps: (1) a spatial and material *arrangement* that would allow the disease and its complications to develop along clinical paths, rather than merely through pathological phenomena, and (2) a *network* of doctors, nurses, patients and diabetes educators, government agencies and pharmaceutical corporations elaborated along the internal secretion of insulin. Significantly enough, the radical reorganization of the hospital and the treatment program has become implicit in the restructuring of the medical paradigm of diabetes, as I will show below.



**FIGURE 1-1** The Suzuran Diabetes Center: old and new

Source: "Ima, genki no aru chūshō byōin wa koko ga chigau: Kanja kyōiku, jinzai ikusei de hatten." (What distinguishes a successful small or medium-size hospital? Along patient training and the nurturing of experts). *Byōin keiei shinjijō*. May 5, 2001. (above); brochure of the Center (below).

### *Arrangements*

"You have to understand disease first of all before you start to build a hospital," Dr. Mihara declared during an interview with me in his second floor office in the old wing of the hospital.<sup>37</sup> He indeed played an active role in designing the new center, which opened in September of 1993 after a complete reconstruction of the old building (see *Figure 1-1*). It was located in the middle of the city, next to Sapporo's downtown, in a neighborhood of shopping arcades, public office buildings and the fish market—a popular goal for tourists and locals alike. Just to the north stretched the famous Odori Park along the main avenue of the city, which was often used as a route for daily walking exercise by patients. Although such a central location may seem ideal for accumulating new clients, Suzuran was located far from the traditional hospital-district of Sapporo. Here, in the downtown, with almost no empty lots left for development, any further spatial expansion seemed to be rather challenging. Nevertheless, the opening of the new clinic was followed by five more stages of smaller-scale architectural innovations in the following years.

The ever-increasing public awareness of diabetes and its complications during the 1990s literally pushed the outpatient clinic into a separate building by turning the whole first floor into a radiology ward crammed with diagnostic facilities: a CT scanner for warning those at an early stage for the risks of intra-abdominal fat,<sup>38</sup> a Doppler ultrasound instrument to evaluate the blood flow in patients with advanced diabetes, and a laboratory for eye examinations, to mention just a few. The third floor, on the other hand, had been slowly giving place to patient amenities, such as a lecture room for inpatient education and a corner for fitness equipment. As a result of these ongoing developments the hospital expanded from a two-floor building to five floors and two wings divided by a corridor on each floor. The new



complex consisted of three main units: an outpatient clinic with more than 2000 registered patients, a 100-bed diabetes ward, and a 40 bed dialysis center making it a medium-size regional institution of its kind (see *Appendix 1-1*).

In the next few years following the opening of the new hospital, physicians who had previously attained prominent positions in the national university's diabetes ward joined the team, and the Suzuran Center began to build a reputation as a highly innovative and patient-focused institution in the heart of the city. It advertised itself as a facility of "total care" (*tōtaru keā*) for the treatment and follow-up of diabetes and its major complications by providing everything from diagnosing elevated glucose levels to complete dialysis care under the same roof. The interdisciplinary team included eight full-time and twenty part-time doctors, fifty-six nurses, radiologists, pharmacists, technologists, social workers and dietitians besides many other specialists. Their self-stated aim was to bring together the education of diabetes and the treatment of its complications under one umbrella by building a web of alliances *around* and allegiances *toward* the disease.<sup>39</sup>

### *Alliances*

It is perhaps not surprising that in the context of the seriously stagnating economy of Hokkaido and the ever-growing political rhetoric of preventive and community health all over Japan, Suzuran tried to step up as a regional center for diabetes care by accepting patients from all over the island. From early on, Dr. Mihara and his colleagues had been stressing the importance of self-care in treating high glucose levels so as to raise the standard of public health in this relatively underdeveloped part of Japan (Monthly Quality 2003).

As a part of this effort, the gradually evolving diabetes education program started to target people from all over the island, especially from

remote places where local health-care facilities—often one retired doctor for a whole town—could not provide any expert knowledge other than prescribing the necessary medications. The so-called "intra-hospital referral model" (*byōshin renkei*) was introduced to encourage physicians in rural communities sending their patients to Suzuran for a complete diagnostic procedure of diabetic complications and an advanced training of chronic self-management. Much of the curricula of this program was adopted from the model developed at the world-famous Joslin Center in Boston, which a small study group of the Suzuran staff visited every summer, thereby constituting the link between international state-of-the-art diabetes education and local health patriotism. By focusing on the chronic character of the disease, the hospital was hoping to form lifelong alliances with patients, physicians from the countryside and internationally respected diabetes authorities, in which each party should have a momentum toward doing diabetes (rather than imposing his/her interpretation on others).

The enthusiastic members of the newly formed patient group, for instance, literally pushed many of the nurses and co-medicals to become more expert, so at the time of my fieldwork, it was required that virtually all employees of the hospital register as a certified diabetes educator (CDE) by passing the national exam. At the staff's monthly workshop, Kikuchi-san, the chief nurse, could proudly report that Suzuran was among the institutions with the most professional diabetes educators per patient in Japan.<sup>40</sup>

While representing public health concerns and reacting to regional incentives, the hospital management also carefully aligned scientific and business considerations in order to carry on as a medium-sized private healthcare institution. One of the devices that made these links possible was the apparatus of clinical trials. The newly regulated and internationally

harmonized system of trials had been launched in Japan in 1997 by the Ministry of Health and Welfare, in order to facilitate the correspondence between global business and universal science under the guidelines of Good Clinical Practice (GCP), a public framework of moral dispositions toward patient care based on the ethical auditing techniques of evidence-based medicine. Suzuran joined the program the following year by hiring two clinical research coordinators (*chiken kōdinētā*). At the time, this may have raised the eyebrows of those skeptical of deferring too much to pharmaceutical companies. However, the close to one hundred and twenty Phase II and III trials conducted annually during the following years turned out to be strong public proofs of the scientifically advanced and innovative healthcare offered at the clinic, which could thus convincingly claim to provide up-to-date medication to its clients. At the same time this synergy also worked toward the justification of entrepreneurialism within healthcare (*iryō*)—a notion that resonates profoundly in the Japanese context of medicine (*igaku*)—by bringing together the pharmaceutical industry, the medical corporation and the ethical discourse of patient-centered medical practice.

Unlike the university hospital, then, where the treatment of diabetes rested upon the convention of separating expert knowledge from physical well-being—X-rays belonging to laboratories; old people confined to bed and never leaving for home—, diabetes care at the Suzuran Center generated a productive interdependence between the infrastructures of treatment and the knowledge about glucose metabolism.

#### 4. Looking for disease (in the wrong place)

My point, which I hope to make clearer in a moment, is that in this new setting medical practices and the internal secretion of insulin came to stand for and mimic each other in numerous ways.

At first, such mimicking was not quite obvious to me. I was looking for people suffering from disease, and I wanted to listen to their stories. Where should I go? I presented the purpose of my research to the doctors, and this is what they said. "Ah, you are an anthropologist, aren't you? You want to find out about the self-care of diabetes, right? Why don't you meet patients at the diabetes training session?" And they introduced me to a nurse who was in charge of organizing the course. It took place three times a day, five days a week on the third floor in a large room that otherwise functioned as the hospital canteen. I was disappointed though. I wanted to see disease and bodies on an operating table, not lay people learning about its mechanism and risks in a plain room on cozy afternoons. As such learning of the disease seemed to suggest, however, that diabetes at the Suzuran Hospital was neither a matter of permanent suffering, nor something to be known in the sense of a target of treatment. It was rather the *act of knowing* itself.

So, I ended up spending most of my time between the third and fourth floors of the hospital where patients were referred by attending physicians of the adjoining outpatient clinic, and by other general practitioners in the city and its vicinity who were related informally to the hospital. Here, they participated in a thorough program that helped them to understand their disease and prepared them against the hazards of more serious handicaps, such as kidney failure, limb amputation, blindness, and cardiovascular events.

Many out-patients were willing to undergo this training even if it meant

sacrificing their little (and mostly unpaid) holiday time to watch videos about handicapped people, and learn to apprehend the sticky blood in their veins through microscopic and radiological images. Their goal was no less than reshaping their lives. Healthy life, as they were reminded daily, was the only way to prevent disabilities likely to occur in the not-so-distant future. It is this liminal state connecting categories of health and terminal disability, and the multiple ways it is mediated by the interaction between medical artifacts, humans, and bodies that drives my interest here. To start examining this in detail, I will now turn to the event in which most patients at the Suzuran Center first encountered diabetes: their admission to the hospital.

## **5. About the quiet old man who didn't know he was sick**

Patients who had been hospitalized entered the building through a backdoor, avoiding the crowds of people waiting for their procedures at the outpatient clinic. The bust of Dr. Mihara's father on the right side and the fact that the hospital staff used this very same entryway fostered informality and contributed to a certain sense of home: a space not so much bracketed off from the outside world—patients could freely go out to the city whenever they liked—, but rather one that was meant to prepare them to inhabit that world by passing through disease and intervening in life.

Imamura-san, a retired *sararīman* in his early sixties, looked worn out and tired as he entered the ward accompanied by his wife and sister to start his two weeks of intensive self-management training. Like many of the other patients at the inpatient unit of Suzuran he had been referred to the hospital by a local practitioner from the small town he lived. Although he had been hospitalized there in a regional hospital for a week with type-2 diabetes, his overall condition did not improve much, so he was referred here to the

diabetes clinic, where his disease could be treated by experts. As it was clear from the referral letter his wife handed over to the young physician—who was now reading it aloud to all of us present—the home doctor believed that a professional treatment program might succeed where his general expertise of internal medicine had failed. Furthermore, he saw hospitalization as a good chance for Imamura-san to improve the control of his blood sugar levels by becoming more attentive to the disease in his body. At the moment, however, he hardly even comprehended why he was hospitalized in the first place.

Now, we were sitting around his bed trying to help him to overcome the obscurity of settling in at the ward: placing his slippers under the bed, introducing himself to the three other patients in the room, and memorizing a long list of medications. Imamura-san was accompanied by his wife and his younger sister. The two of them did most of the talking with the physician about the treatment, and with the nurse about the rules and daily routines of hospital life, while Imamura-san sat listlessly on the corner of his bed. I was sitting right next to him, taking notes in a vague hope of finding some clue to his disease. But before long, I began to realize that as far as diabetes goes, the others had much more to say about.

"So, Mr. Imamura, I see that you have been diagnosed with diabetes three months ago...?," the doctor asked with a touch of mild encouragement in his voice. The patient nodded.

"My husband was hospitalized in Iwamizawa<sup>41</sup> for a week," the wife said, "but there we were told that he needed to learn (*benkyō*) more about diabetes, so they sent him here for the general checkup... But he quit smoking, and he drinks less than before, thanks God. He used to drink five cans of beer an evening! But now, you see doctor, he's really worn out." Imamura-san's weakness and underweight was most tellingly revealed by his

oversized pajamas. The physician turned back to him again:

"I think the best I can do is to schedule you for some tests to make sure that the sugar in your blood hasn't done any irreversible damage. You have to understand that diabetes can have some very serious consequences, if you are not cautious enough. What we will do is teach you how to live with this sickness (*byōki to no tsukiaikata wo benkyō shite morau*), and how to avoid those nasty complications."

Imamura-san nodded again, and in a low voice he added that he felt quite sleepy (*darui*). His sister whispered something to the wife next to her that nobody in the room could hear. We saw them off to the elevator, where the wife hesitated for a moment, but then turned to the wordless doctor pleading to make his husband somehow "follow the disease" (*byōki ni shitagau*).<sup>42</sup> The nurse answered instead. She quickly reminded the relatives that the cure of disease was more than a matter of doctors treating and husbands following it. It was, significantly, a family affair. She suggested to Imamura-san's wife that she might find out about diabetic recipes ("There are many interesting books about nutrition in the bookstore right at the corner!") and scheduled her for a counseling session with the dietitian for the following week to consult her about the daily calorie intake Imamura-san's diet required. "Your husband will rely on you for medical attention...and patience, of course, for a permanent treatment," she told the wife in a kind and calm tone.

In the meantime, Imamura-san had his first taste of, well, following his disease. A blood sample was taken from his left hand, the first in a series of tests performed in every two hours for the next day in order to grasp the rates of glucose uptake and insulin secretion in his body, which is supposed to be strongly influenced by the food eaten during the day, and the calories burnt

by exercises and other activities. So, the nurse immediately noted: "You will find the meal in the canteen a bit unusual, perhaps even tasteless. But try to eat as you would normally do during the day." She stressed "normally" twice making the point that the treatment of his disease must start from Imamura-san's own understanding of it as part and parcel of his own life. If the medical staff needed to know the ups and downs of the patient's metabolic rate in order to grasp the pathology of his disease, the shortest way to such a knowledge led through a normal day in Imamura-san's life. And who else would know it better than Imamura-san himself?

When the nurse had finished testing, she pulled out a checklist from the patient's files, which included various questions about his disease ranging from normative ("Can you name the three major complications of diabetes?") to more descriptive ones ("Do you suffer from any diabetes related complications?"). This so-called hospital admission checklist (*tōnyōbyō kanja nyūin kyōiku chekku risuto*) was the other ritual procedure besides blood testing that each patient had to go through during the first day of his or her stay in the hospital. It consisted of two sheets and was intended to measure the severity and frequency of symptoms as well as to gain a picture of the patient's daily activities. The answers were keyed not only to pathological scales of diabetic disorder, but also to the patient's ability to manage his/her chronic condition.

The nurse started to question Imamura-san about his condition in a well-established way I had seen several times before. With her professionally gentle voice, she was trying to ease the air of tension palpable in the room.

*Nurse: Don't worry, it's not a test, try to answer as honestly and truthfully as possible. Do you know your ideal weight is?*

*Imamura-san: Well, I used to be 76 kilograms for many years, it was the best...*





far from impressive. Frankly speaking, Imamura-san had hardly any answer worth recording. He knew more or less how many times a day he ate, for example, but he couldn't—or didn't want to—recall what exactly. He vaguely remembered that his former doctor mentioned something about too much sugar in his blood, but he never heard about glucose levels, not to mention other diagnostic values of diabetes, like hemoglobin levels in blood cells or skin disease on his feet. Most strikingly of all, he had hardly anything to complain about except getting easily tired and visiting the bathroom too often, although the latter was more a complaint of his wife, he added, than his own. "To tell you the truth, I wouldn't really care about it myself. I mean, doesn't just everybody get up to pee in the night? Is it something you go to the doctor for?" Nevertheless, the nurse quickly added this to the list of symptoms and reminded the patient to report every time he visited the bathroom during his stay in the hospital.

Before finishing the orientation, the nurse explained the training program that awaited Imamura-san. Blood tests six times a day, a full body check-up and lab tests to identify potential complications of diabetes, group sessions three times a day, consultation with a dietitian, individual training in self-monitoring blood-glucose levels and, if necessary, injecting insulin. Imamura-san was puzzled though to hear that he had to *know* all this. He had hardly any knowledge, let alone interest in medicine, and, he added slightly lowering his voice, he even had to ask his wife to prepare a list for him to help answering a former doctor's meticulous questions about his own eating habits. Habits he had to change from now.

I followed the nurse back to the nurse station. She placed the bottle containing Imamura-san's blood sample onto a tray, took a print out of a drawer and posted it on the wall among other similar prints with patient

names. These were medical records that summed up the results of the two-hourly blood tests performed during the first twenty-four hours on every newly admitted patient for an assessment of their glucose secretion and insulin sensitivity. Such diagnostic tests were called *tāges*—referring to the German word for 'day'—among the medical staff, and their results were considered as the basis for further medical intervention. The form for these tests had boxes filled with numbers and a blank diagram for charting the results on a curve and compare its peaks and valleys to other events of the day, like 'lunch', 'nap', 'snack', 'walking' or 'pain in the stomach'.

Needless to say, Imamura-san's chart was still empty like most of the checklist of the diagnostic interview. Neither he, nor his doctors had much to say about anything worth of calling a disease (except perhaps a referral letter and an anxious family). Yet, on the chart at least, there was already a *space for the interrelation* between these two ways of knowing diabetes: glucose levels—measured in mg/dl—and the awareness of the metabolism—verified in interviews and in routine daily encounters with patients.

The medical record, on which the significant metabolic processes of diabetes were slowly becoming visible, fed into the very constitution of its facts and events (Berg 1997; Jensen 2010). Diabetes was thus from the outset embedded in a process of mapping emergent medical and subjective understandings of the disease onto each other. As we shall see shortly, in the practices such metabolic disorders were making surface many things became linked together: sugar levels with meals, insulin with working hours, normal present with pathological future, to mention just a few. That is, talking about the metabolism and living with it were embedded in the organization of treatment and allowed for new ways of actively engaging the body through "following the disease," as Imamura-san's wife put it.

## CHAPTER TWO

### Metabolic Encounters

*in which food is objectified and lifeworlds become complicated*

*"The world is based on the limits [thalasth]," said an old Kabyle. "Heaven and earth are separated by the limit. The eyes have an enclosure [zerb]. The mouth has a limit. Everything has a limit."*

—Pierre Bourdieu

The idea I have started to develop in the previous chapter is that the fact(s) of diabetes are deeply interwoven with the practices in which it is encountered. Following on, this chapter will introduce the key aspects of training patients to manage and control high glucose levels.

From the novel organizational and material arrangements of the hospital to the emerging alliance of patients, health care providers, researchers and the medical industry, specialized diabetes care in Suzuran was centered around the accumulation of scientific knowledge and lay experiences of the metabolism. Both are essential for the treatment of diabetes, but assembling them is far from straightforward. As we have seen, some patients arrive without much of an idea of what is happening inside their bodies. By the day of discharge from the hospital, they are expected not only to recognize, but also to be receptive to the complicated metabolic processes that cause their ill health.

The place of disease, for the time being, becomes a place for learning. Patients—along with the medical staff who coordinate their care—try to learn how to make sense of and live together with their metabolism.

## 1. Patient education

Although the treatment program at Suzuran Center was constantly changing before, during and after my fieldwork, it preserved some of its key aspects until today.<sup>43</sup> First, that diabetes is a metabolic disorder that usually cannot be explained by one key factor, so the linking of multiple factors (e.g. genetic or immune cause) and the understanding of their relationships is crucial for the success of treatment. Second, that diabetes cannot be cured only controlled to avoid complications. There is no single therapy, only a web of therapeutic options (e.g. nutrition, exercise, or drug therapy) firmly grounded in the self-management of this chronic condition. And third, that it is because of the very complexity of these etiological and pathological aspects that the treatment of diabetes requires not only a large pool of professional experts, but just as much a permeability between these different fields on the one hand, and between expert and lay knowledges on the other. This third aspect has been referred to as 'total care' (*tōtaru kea*) or 'comprehensive treatment' (*sōgōteki iriyō*).

Thus, the treatment of high glucose levels was institutionalized in a routine of confronting "subjective" feelings (in patients) and "objective" findings (in laboratories) and the hierarchy between the two was far from settled. As far as diabetes was concerned, the particular disorder of any one person was revealed, understood and diagnosed through the meticulous process of his or her acquiring of the general ideas and specific skills of living with such a disease.

Instead of *confronting* patients with numbers and facts of biomedicine, however, diabetes treatment was a process of "learning to be affected" by the disease (Latour 2004). The 14-days treatment program was made up of two main parts: a general screening of diabetic complications, which took usually

two to three days; and a diabetes training course designed to assist patients in implementing lifestyle changes: walking after each meal, counting calories, and measuring blood-sugar levels three times a day. The latter included an intensive education program of three classes per day for a two-week period, and further individual (or family) sessions of dietary counseling, training of blood glucose measurement or insulin administration, when necessary (see *Appendix 3-1*). Most inpatients completed the program in two weeks, but some of them left it earlier after finding out that their condition was better than they originally thought. Yet others, especially older patients, chose to stay longer and repeated the program several times, because they, or their family, felt they could not manage the disease successfully by themselves.

To investigate this matter further, I will focus on two essential steps in the organization of diabetes treatment at the Suzuran Hospital: eating and diagnosing complications.

## 2. Learning nutrition

*Gohan de wa arimasen. Eiyō desu.* [No, not food. Nutrition].

—Dietitian at the diabetes education class in Suzuran Center

One, if not the most, important of the ideas surrounding diabetes in the clinic was nutrition.<sup>44</sup> The implication seemed to be as simple as that: nutrients and chemicals necessary for maintaining life functions are derived from food, so consuming it is strongly related to states of health and disease. Eating and the attention to what and how one ate were of the greatest importance in the treatment of diabetes. From the very first event of hospitalization—the blood sugar monitoring tests on the first day—food was situated at the moment of knowing disease and the conditions of doing it.<sup>45</sup>

When people eat, patients were told in one of the afternoon classes of the group lesson, the nutrients in food are broken down into their basic units that their bodies need for daily functioning. Carbohydrates, like rice, bread and noodles, for example, are turned into sugars after digestion and then released into the bloodstream. This sugar in the blood, called glucose (*kettō*), stimulates the pancreas to secrete insulin, a hormone that in turn helps glucose to pass from the blood into cells where it is converted into energy. Glucose levels vary throughout the day. The dietitian added: "This is the natural state of daily life, a central factor in the incorporation and digestion of food, which we will call 'metabolism.'" So, it is normal that blood sugar increases immediately after meal, but then it returns to a relatively low level of 70 to 110 milligrams per deciliter. Well, that is if you are healthy. "But the case with you," she continued, "is slightly different. Because your body fails for one reason or another to produce the insulin you need, so the glucose in your blood is not converted into energy. Or at least not in the necessary quantity. This is why your blood sugar is higher than of most healthy people."<sup>46</sup>

In popular books, academic conferences and at the clinic, diabetes was revolving around food and eating: diet histories, food circles<sup>47</sup>, calorie calculators, glycemic indexes, dietitians, nutritionists, and long lists of food prescriptions (but, contrary to the common belief, very rarely prohibitions!). Since many patients arrived at the clinic with a medical history of obesity and an expressed concern about their weight, the talk about food, underpinned by the scientific language of nutrition, was an entrance into the medical practices in which diabetes was gradually unfolding. During the next two weeks, patients participated in nutrition therapy that required much more than blindly following dietary prescriptions. They were required to eat their meals together in the communal canteen, to calculate the calories taken in as food

and burnt during the rest of the day, to learn associating the main categories of nutrients with certain foodstuffs, and to see the various links between all this and their everyday lives.<sup>48</sup>

The simple act of eating food, interestingly, led not only to the awareness of the metabolic activities inside one's body, but also to the process of making clinical knowledge about it. Eating normally "like any other time," as the nurse reminded Imamura-san, made diabetes speak both to the patient and the care professional. More than that, it enabled them step by step to speak to each other as well.

But not yet.

#### *How to eat better?*

I came across such "food talks" in the canteen during meal times, while having my lunch—not too restricted but slightly adjusted to the patients' strict diet. Nurses and dietitians (and less regularly doctors) visited the dining hall once or twice a week to sit down among participants of the program for some talk over lunch. In these conversations, patients contrasted the flavorless salad to the pickles (*tsukemono*) they were eating back home, or the small size of the fish on their plates to the variety of sushi at the family dinner table. A nurse in addition was explaining how food portions were calculated according to each patient's normal calorie intake which was said to be different from person to person.

By far the most recurrent concern among these complaints was the blandness of the *miso* soup, a part of almost any Japanese-style meal. The medical staff, in return, tried to encourage people to make a virtue out of necessity by forming a habit of drinking bland *miso* soup (*usuaaji no kuse wo tsukete kudasai*). There were at least two normalities in conflict here: one for the



calories, and one for the patients' eating habits. Although such norms did not necessarily fit nicely together, they were interdependent and overlapping; or it might be better to say that they *became* interdependent in the clinical and metabolic encounters with diabetes (Mol 1998).

It was there in the canteen where I met Sato-san, surrounded by nurses while slurping his noodles. He was after a serious operation—in a different hospital—of removing a part of his pancreas due to cancer. Although his look, which kept switching between me and the ceiling, struck me first as a bit mad, later I witnessed him injecting insulin, in which he was more prompt and competent than most of the doctors at the clinic. Besides such an expertise, he was also famous for being the first to finish his meal. The dietitian at his table cautioned him day after day that eating fast made it harder for the insulin in his body to react, and contributed to his high blood sugar levels. He was listening, but in the end, he had to admit that it was the only way he could eat. He had been a *sararīman* for all his life, he explained, which meant he had hardly ever more than 15 minutes for a lunch. The rest of the lunch break, if there had been indeed, was saved for a short nap. "This is how I eat," he added. It seemed to cause little problem for Sato-san though, for insulin shots helped him to regulate his blood sugar with a proficiency that allowed him to eat as he liked.

Normal calorie intake was thus not simply a matter of volume. It was also a matter of *how* one ate, *how many times* and of *how much* of it she burned in her daily activities. It was a matter of what medications he was taking, and what kinds of foods she liked. Above all, it was a matter of taste. Food, and consequently blood sugar, had to be monitored mostly and increasingly by the patient who supposedly knew the most about what he was eating. In other words, normal calories had to be related to one's own normality by

knowing, mastering and feeling what health care professionals would call, for the sake of simplicity, "nutrition."

*The way from the scientific to the social (at times) leads through the individual.*

The diabetes management manual patients received at the admission to the program and carried with them everywhere was quite explicit about this:

Nutrition therapy is the cornerstone of the treatment of diabetes. No matter how competently drugs are applied, if they are not supported by adequate food, diabetes cannot be cured. However, current diabetic diet corresponds to the well-balanced daily caloric intake recommended for healthy people who want to lead a normal life. So, try to make it your own! (Educational material for the diabetes treatment program at Suzuran Center, p. 21; translated by the author)<sup>49</sup>

#### *The nutrition counseling session*

Strict individual diet therapies common in American clinics, where critically obese patients are literally referred to fasting was unheard of at Suzuran. A more common approach was the regular nutrition counseling held at the dietitian's office under a huge poster of the food pyramid that each patient was supposed to memorize by the time of discharge from the hospital (and very few of them actually did). These interviews had a routine format starting with (1) a clinical review of the patient's diet profile, followed by (2) an explanation of the general facts of medical nutrition therapy (MNT, *shokuji ryōhō*), and concluded by (3) the minute planning of a personalized dietary management including the content and timing of three daily meals and snacks. While in the initial session the emphasis was usually on the first two steps, the following meetings were increasingly concentrating on the establishment of a new habit of eating located in the sick body.

The dietitian (*ei-yōshi*), whose sessions I happened to visit that day,

placed particular emphasis on the assessment of the diet history of her patients. She was asking detailed and personal questions from each of them, such as "How many liters of milk do you usually keep in your fridge?", or "What is the size of your *chawan* (rice bowl) at home? Do you know how many bowls you would eat a day?" She went on asking them about their eating habits from childhood on and the number of eating out occasions and convenience store *bentō* (lunch box) per week.

"You see," she told me between two sessions, "this first step is very important. Because I want to show them the cause of their disease, I want them to feel how personal it is to handle it." I was a little disappointed by her strategy. I came here, because I wanted to know about nutrition, but she was talking about personal memories.

"Do you think it helps them to understand anything about the mechanisms of glucose regulation?" I asked her. "Maybe not, but that's beyond the point. It's me, first of all, who has to discover what happens in their bodies. But to do so, I need to know what they have been eating. Something only they will know. So, I make them remember." Well, some of them, especially men, did not remember at all. They came with their wives who talked about their husbands' food habits (*shoku seikatsu*) instead. In other words, about their nutrition.

Calories, next, were calculated per day for each patient using the so-called "food exchange lists," which had been developed by Japanese nutrition specialists back in the 1960s (Tsuda 2003). The "Food Exchange List" (*Shokuhin kōkan hyō*) is the primary manual for dietary advice in Japan (Japanese Diabetes Association 1965: 76). It includes more than 600 food items—most of them "Japanese food" (*washoku*), the dietitian reassured elderly patients—organized into six groups according to primary nutrition ingredients. It has

been revised every 5 to 10 years to reflect current trends and research developments in nutritional science and epidemiology; by the time of my fieldwork, the sixth edition was in use (Japanese Diabetes Association 2002). The most peculiar feature of this book was that calories and grams rarely appeared on its pages: the tricky equations of energy and weight<sup>50</sup> were eliminated and exchanged into a figure in which 'one unit' equaled 80kcal. It was this unit that described the energy requirements of individuals *and* the amount of food throughout the book. So, once memorized, patients didn't need to struggle with the more difficult four-digit figures.

At the nutrition interview in Suzuran, the daily amount of each nutrient group was decided on the basis of the patient's condition and diet history: first, it was expressed both in terms of units and the amount of each food item in order to reduce each foodstuff into one-unit-amounts. For example, in the case of scallop, 120g equaled 1 unit, that is 80kcal of energy, making up more than half of the protein requirement (Group 3) of one meal for an average adult person. But if you didn't fancy Japanese delicacies all that much, there were fruits too in Group 2. Half an apple (75g) was 1 unit of carbohydrate. To make all this general knowledge useful and relevant, nutritionist at the Suzuran designed a simple exchange meal table that was preferably filled out by the patient according to her own choices of food (see *Figure 2-1*). If she couldn't do it at first, she was asked to take the sheet with her and complete by the next session. As most of the content was based on the food provided by the hospital, it was a routine job for the dietitian to check it and give further advice.







糖尿病食の指示表									
★あなたの1日の食事は、表の通りです。指示エネルギー量（ kcal ） 1日の単位（ 単位）です。									
	食 品 分 類（群類別）		1日単位	朝 食	昼 食	夕 食	間 食		
表 1	穀・芋・豆 	炭水化物							
表 2	果 物 	炭水化物							
表 3	肉・魚 貝 卵・大豆 	蛋白質							
表 4	乳 	炭水化物 蛋白質・脂質 ミネラル							
表 5	油 脂 	脂質							
表 6	野 菜 	炭水化物 ミネラル							
調味料	調 味 料 								
< メ モ >								病院	栄養科

FIGURE 2-1 Meal table used by patients of the Suzuran Center

The so-called *Exchange Meal Table* used at Suzuran Hospital during my fieldwork (Courtesy of the Center)

### *The object of food*

The therapeutic goal was, then, a restructuring of the patients' eating habits on the basis of the scientific model of balanced nutrition and his or her own memories of food, and it was in the clinical practice of diet therapy that these two trajectories happened to reflect each other, whether in conversations at the dining hall, or on the exchange lists of nutrients. Routines of eating, through a scientific language of nutrition, allowed both patients and their care-givers at the clinic to slowly formulate the twofold truth of metabolizing food. This constant encountering with one's own metabolism points to the implicit intersections between the symbolic meanings of healthy food stressed by structuralist approaches (Douglas 1966; Lévi-Strauss 1969) on the one hand, and the lived experiences of eating revealed in more

phenomenologically oriented ethnographies (Sutton 2001).<sup>51</sup>

In their daily struggles for normal blood glucose levels, patients were eagerly (or less eagerly) learning to feel the differences between 'good' and 'bad' foods. Clinical interviews, classes and meal plans were all designed to ensure the proper amount of energy intake and the balanced proportion of the three main nutrients (carbohydrate, protein and fat) and that of vitamins, minerals and fibers, and to map out the singularity of each food item on the mechanism of the disease. The more patients became sensitive to such *proper* ways of eating—and later in the program exercising, sleeping, taking medication, etc.—, the more they and their doctors were able to explore about the specific condition of their disease. The Food Exchange List gave a plain definition of what 'proper' should mean for people with diabetes:

(...) the appropriate amount to simultaneously achieve two goals; firstly, to supply diabetic patients with the necessary nutrition to maintain the physical condition of the patients to enable them to continue regular social activity and secondly, to abolish the lack of insulin action which causes diabetic symptoms including long term complications. (Japanese Diabetes Association 1965: 5; cited in Kitamura 1994: S234)

The normalcy of a socially active day in life and the normal daily fluctuation of blood glucose levels were ultimately linked up in the clinical practices of objectifying food. The dietitian and her exchange lists were crucial in this objectification, but only as long as they meaningfully related to Sato-san, who could not eat his lunch any slower, or Tachibana-san who, after all, took her regular walk to the nearby convenience store for her daily cracker (*senbei*). For them, having a disease, was just as normal as the glucose levels in their bodies were pathological in any biological sense of the word. Patients and their caregivers accepted that these two hung together.

### 3. Glycemic thresholds

Disease, in these nutritional encounters, was becoming less a pathological state, and more the momentum for avoiding future health problems. Patients who were seeking treatment for diabetes were situated at one end of a spectrum by learning to prevent future complications. Those with heart disease, kidney failure and nerve disorder were at the other end. This continuum between diabetes and its complications was, however, not so much defined by its ends as by its means and mechanisms. It was performed in routine diagnostic tests each patient had to go through as a part of the diabetes treatment program.

Here, normalcy was not measured in hours between meals, but rather in years between the disturbance of glucose regulation and the manifestation of its consequences: five years in the case of nerve damage (neuropathy), seven for eye disease (retinopathy), and ten for kidney disorder, according to long term clinical trials (Sakamoto 1999).<sup>52</sup>

The central problem of early researches on diabetes following the discovery of insulin was to find a common goal of treatment. Is it the lowering of glucose levels by tight control? Or the helping of patients to live a fairly comfortable life? Since the 1980s, various so-called prospective clinical trials have been set up in Japan and elsewhere to put an end to the long-standing controversy between advocates of "symptomatic" and "tight" control. To do so endocrinologists decided to assess the risk of complications in patients treated with intensive therapy and those in a control group. A parameter called glycemic threshold was proposed as the golden standard for choosing between treatment options. This is usually a given blood sugar level—established in a controlled trial—above which a certain sort of diabetic complication is supposed to be life-threatening. So, for example, according to the

Kumamoto Study conducted in the early 1990s,

it is clinically important to indicate the glycemic threshold to prevent the development and progression of diabetic microvascular complications. (...) no worsening of retinopathy and nephropathy was observed in type 2 diabetic patients whose HbA1c, FBG [fasting blood glucose], and 2-h postprandial blood glucose concentrations were below 6.5%, 110 mg/dl, and 180 mg/dl, respectively. Therefore, in the present study, the glycemic thresholds to prevent the onset and progression of diabetic microvascular complications are indicated as follows: an HbA1c level at least <6.5%, FBG <110 mg/dl, and 2-h postprandial blood glucose concentration <180 mg/dl. (Shichiri et al. 2000: B27)

As the results of prospective trials like the Kumamoto Study have been accumulating, it proved to be more and more difficult, however, to find any meaningful relationship between such values. As the authors of the above study further note:

These glycemic thresholds suggested by the Kumamoto Study might possibly be oversimplified because of the analysis of the data with smaller numbers of patients studied. Epidemiological analyses of the DCCT and UKPDS data showed a continuous relationship between the risks of diabetic microvascular complications and glycemia, and there was no evidence of any glycemic thresholds for any of the microvascular complications above normal glucose levels (2,16,19). Therefore, the epidemiological analyses suggested that by whatever means, intensive therapy with the goal of achieving normal glycemia should be implemented as early as possible in as many type 1 and type 2 diabetic patients as safely possible. (Shichiri et al. 2000: B27)

An intriguing issue, nevertheless, remains. If glycemic threshold didn't turn out to be the appropriate parameter medical researchers were eagerly looking for, it has unquestionably become a distributive tool in clinical



practice.<sup>53</sup>

Complications, at the Suzuran Center, were a matter of choice between treatment options: how, when and where to intervene? This time not in the design of clinical trials, but in the everyday life of patients. And it was glycemic threshold—or its pragmatic use at the clinic—that mobilized the scientific knowledge of complications into a mode of disease that was easy to establish as a practical concern of self-management.

Doctor to the patient after a quick look at her blood results: "It's your hemoglobin [A1C] levels that keep worrying me. If they continue to be above 8 for more than six months, your kidney will very soon stop working properly... The results of your eye exam are not too good either. I don't want to terrify you, but you should really be more serious about glucose control."<sup>54</sup> For patients, thus, the diagnosis of complications was a critical point of entry into the world of diabetic life.

#### **4. Diagnosing complications**

This local distribution of the risks of diabetes over individual bodies involved a variety of diagnostic techniques and procedures, in which the treatment of disease was established as a lifelong connectedness between patients and ageing body parts. I turn next to a brief description of three of these routine tests of long-term complications at the Suzuran Center: the eye examination, the ultrasound of blood flow and the laboratory tests of kidney disease. My aim is to show how disease was increasingly becoming a practical concern in the course of distinguishing between disability and health.

##### *The eye exam*

Angiography was one of the most common diagnostic tests for people with

diabetes. One explanation for this might be that eye disease is the fastest developing complication, and most patients will have spent years with high blood sugar levels before they see a specialist. The most serious among diabetic eye complications is retinopathy, and, as we have seen above, it is a common target of clinical trials.

It is important to see that most patients visit general physicians who see diabetics day after day and refer them regularly to the ophthalmologist. The result of such tests, however, plays hardly any important part in the treatment of diabetes, unless they are really bad. In the Suzuran Center, in contrast, the ophthalmologist office was set up on the first floor so that the daily routines of glucose control and the future likelihood of vision loss could be aligned in the process of identifying long-term complications.

The thorough eye examination of the inpatients started with reading a chart to determine eyesight, followed by simple questions about occasional pain or blurred vision. Most patients, however, had no complaints worth mentioning. When the doctor finished questioning, the nurse handed her a magnifying instrument (ophthalmoscope) that allowed a simple look inside the back of the eye. "I don't really like this technique," the doctor told me in an interview, "because the patient cannot follow the procedure with his own eyes. I can see something, but it's invisible for him. So, we become kind of separated."<sup>55</sup>

Luckily for her, there was a way to restore the link between patient and disease, called fluorescein angiography. This was an exhaustive imaging of the retina. The nurse injected an orange dye (fluorescein) into Kato-san's arm, which, circulating through the blood vessels in his eye, made damages visible on a special photograph. More than simply being restored, the character of the link between patient and disease has changed. Now, he sat next to the doctor

and they talked about the *same* disease on the picture.

*Physician:* Here, here, can you see that this part of your eye is slightly different from the rest? Here, the vessels are swollen. You can't feel it, but it may burst. Of course, I can't tell you when, it may take years from now.

*Kato-san:* What happens when it bursts?

*Physician:* Well... then the blood will block the passage of the light to your retina. In the worst case, you can become blind. But no worries. We can treat it with laser if you want.

*Kato-san:* That sounds good to me.

*Physician:* But that treatment would just be to reduce the risk of a rapid vision loss. To really slow down that process, you have to try to keep your blood sugar close to normal.

Kato-san, as many other patients, was called on as the very agent of relating abnormal blood vessels in his retina with his daily life in which normal glucose levels mattered, or so he was told, a lot. The angiographic image thus localized (the risk of) diabetes in the back of the eye in a simple anatomical mode. But the mundane steps of the eye exam pointed to a somewhat more complex articulation of the disease where experts, patients, instruments, numbers, chemicals, body parts, and their pictures, together, fused normal —i.e. below the glycemic threshold—glucose levels and the fear of retinopathy into the singular object of treatment: diabetes.

#### *Vascular ultrasound*

There were yet different notions of the body much more difficult to assess and render compatible with disease. Blood, for example, which keeps flowing through one's veins overloaded with sugar. Contrary to most previous research on diabetes complications that have located its risks in the finer

vessels of the eye, the kidney and the feet, recent studies established that uncontrolled sugar levels play an equally, if not even more, critical role in macrovascular problems all over the body. Most complications related to diabetes are due to either a thickening of the walls of blood vessels (atherosclerosis), or slower blood flow. The latter, in turn, is generally due to a surplus of sugar in the red blood cells, which increases the viscosity of the blood.

In the radiology department, diabetes was engaged in a more elaborate way than in the adjoining office of the eye doctor. Disease here presented itself not in a localized form, but as that of *blood fluidity* throughout the whole body. The technician explained the subsequent procedure with a help of a colorful brochure to the patient. He was going to perform an ultrasound to evaluate blood flow in the limbs, because bad circulation in these veins may indicated more general vascular problems, or even a high risk of cardiac infarction. Moreover, it was a very safe technology, the patient lying on an examination table was reminded, because it used sound waves instead of X-rays to determine the velocity of blood.

Next, the radiologist put a jellylike thing on the left thighs of the patient and placed the handheld sensor over the skin. By passing the instrument up and down along the leg, the sensor sent and received sound waves that bounced off the blood cells flowing through the vessel below. The movement caused a change in pitch of the reflected sound waves (called the Doppler effect) that was then amplified through a microphone and then brought into view on the screen above the patient's head.

Compared to the previous eye exam, there was almost no talk here. We could clearly hear the swishing noise of blood passing through the patient's veins, and the anthropologist along with the technician could see the bright

colors on the screen that represented the speed of blood: blue when flowing away, and red when flowing towards the sensor. But the patient couldn't see anything this time, for he was lying on his back. What he was shown after the test were a couple of graphs that had been generated by the computer from the ultrasound images. But this time he was left without any further explanation.

It may be that there was no need for explanation, indeed. After all, the sound of blood flow represented a lot more than any information technicians and nurses could have come up with. They brought out the totality of diabetes over the whole body through an entire lifetime, as long as blood was flowing through one's vessels. Simultaneously, this routine diagnostic procedure attributed properties to this totality of disease so that it could be personally dealt with. Patients embodied their disease in so far as the blood in their veins—its velocity, thickness and flow—could be monitored and managed.

The sheet with the graphs of blood flow were inserted in the patients' file next to other results and traveled to different sites of the disease: late-afternoon decision-making 'conferences' (*kanferensu*) on the second floor where further treatment options were decided; examination rooms where drugs were prescribed to prevent the complications indicated by such results; or laboratories where findings were compared with other hard data being far off removed from flesh-and-blood patients.

#### *The microalbumin test*

For most patients at the Suzuran Center, the second day started with a simple urine test. They were instructed the previous night to collect their morning urine in a container. Various values had to be assessed from this sample, but

most patients gave little or no notice to it at the time of the actual testing. After it had been handed over to the nurse, the white paper cup was brought to the laboratory in the other wing of the hospital building. As a part of my field research, I accompanied patients through the long series of diagnostic examinations, but here I had an obvious problem of directions. Who should I follow? The patient? Or the nurse? As for the former, I could return to her room later in the day for further talk. So, I decided to follow the nurse with the tray of urine samples in her hand. Sticking to the urine containers, after all, seemed to be the shortest way for an anthropologist like me to the laboratory.

The hospital laboratory at Suzuran Center was adjacent to the outpatient ward, *not* a place for science. Actually, there were rarely any researchers or doctors present. Most of the work here was done by technicians, nurses and diagnostic equipments, such as blood analyzers that could perform twenty-something different types of tests on a tiny drop of blood. The urine test, however, required a little more calculation and coordination between medical professionals, human bodies and test strips.

Entering the small testing room, the nurse introduced me to a technician who conducted urinalysis of a protein to detect kidney problems. She explained her work with a touch of enthusiasm: "Kidney disease is extremely difficult to detect, because its symptoms are so vague. You must have seen yourself that physicians pay much more attention to problems with the eyes and feet, because those are what most worry diabetes patients. But I tell you that the kidney is much more serious!"<sup>56</sup> She inserted a chemically treated testing paper into the sample. This piece of paper was the key element in differentiating sick kidneys from healthy ones, which, in the early phase of disease, required a high level of accuracy. In the hands of an expert the test

strip could determine the presence of very little albumin in the urine.

"Albumin is a protein that is normally filtered out by the kidney and returned to the blood," the analyst went on with her explanation, "but when the kidney doesn't function properly, it leaks into the urine. First, only in a small amount, but this is the very sign of early kidney damage. And that's why you need a very precise measurement."<sup>57</sup> Yet, there was a controversy between doctors and technicians over how far, in fact, one had to go with such preciousness. The difference between disease and health, that the "small amount" of albumin was alleged to indicate, cut through various interests in the hospital hierarchy. Albumin levels in the kidney vary throughout the day depending on the food and liquid the body takes in, the age and weight of the patient, and, to make things a little more complex, on the very progress of kidney failure that is being screened. "That's why," and the lab analyst referred me to recent scientific articles in her computer, "a 24-hour urine collection is the gold-standard for assessing such daily changes accurately."<sup>58</sup>

Later, I found that nurses and doctors were reading different articles, and what is more important, they had different stories to tell me about albumin. Physicians were recalling their struggles with hospital management for conducting such expensive tests. The medical assumption of kidney disease was based on the idea of progressive loss of function and the level of albumin was a marker of such progress. 300mg/L on such a scale was located 10 to 15 years closer to the total loss of renal function than the critical level of 30mg/L (called microalbumin). Because standard dipstick methods could not detect such low levels accurately, physicians ordered the more expensive albumin-specific test strips. Considering the relatively few positive results, however, the cost of the microalbumin test caused quite a headache for the management. They tried to push clinicians to follow the cheaper technique

recommended by the Ministry of Health and Labor for the diagnosis of kidney failure. This traditional method could assess albumin only above 300mg/L, which was considered to be "too late" for effective intervention by physicians.

Another context in which the 24-hour urine collection came under increasing pressure was that of nursing work. Nurses had to collect urine samples from old patients or young children, who were usually unable to do it properly themselves. Needless to say, it was a rather messy and cumbersome job. Using a catheter was one obvious solution, but there happened to be even cleaner ones.

*The microalbumin:creatinine ratio.* These different but related criticisms of the inconvenient and unprofitable testing were not a matter of dispute among professionals in a simple sense of communication. If anything, a common object was missing from the daily practice of diagnosing kidney failure. In the laboratory, urine was a sample with more or less protein in it, while nurses at the bedside (in the toilet?) saw it as a dirty thing, before anything else. Physicians, meanwhile, did not see urine at all, they saw suffering patients. The technical innovation that enabled the *correlation* of such different objects was the so-called albumin-to-creatinine ratio (ACR), an algorithm that not only seemed to ease the tension between the parties involved, but provided them with a common sense of purpose as well.

The analyst showed me the so-called microalbumin assay, a technology that quantified all the "organizational" and "bodily" tensions into a relatively simple procedure. Albumin examination was supplemented with a measurement of creatinine, a byproduct of muscle metabolism. Creatinine is normally excreted into the urine on consistent level—although significantly different in men and women—making it into the ideal factor for correcting the



daily variations of albumin. Such facts of the metabolism were linked up with daily routines in the hospital, as the scientific article puts it in the language of endocrinology:

For the early diagnosis of diabetic nephropathy, it is best to use the albumin excretion rate (AER). However, *it is a complicated test to perform in the outpatient setting*, and it is sometimes affected by inaccurate urine collection. Therefore, we have used the albumin/creatinine ratio, which is measured simply with randomly collected urine, for evaluation of microalbuminuria and found it to be of equal diagnostic value to the AER. (Yamaguchi and Kadono 1991: 283)

The albumin/creatinine ratio quantified the overlapping professional and metabolic complexities outlined above in a particularly simple and compelling manner. First, it required only one random urine sample which persuaded most participants from managers to technicians. Second, by measuring the level of creatinine this spot value was translated into the total daily amount of protein in the urine "flattening out" the daily changes of albumin levels. Third, such fixed values of daily variations made long-term changes of ageing more comprehensible for the patient and more comparable with other populations for the epidemiologist.

## **5. Between disability and health**

Ultrasound, angiography and urine tests assembled different facts of a single person, but these facts were rarely drawn together on individual patients. They instead allowed disease to implicate categories of health and disability on the body public.

The threat of (more) serious diseases was in the focus of diabetes

treatment from early on, as I have tried to show. First, in the repetitious rituals of screening complications, and next trying to grasp one's impaired metabolism from such results. That is to say, diabetes was a sort of disability. It was even written in the law. Those who become blind, dependent on dialysis, or lose a limb after many years of struggling with complications were registered under the specific condition of their disabled body part and issued a so-called disability certificate receiving points for each handicap they had (Kifune 1996: 421).

In contrast, diabetes itself was treated as a chronic condition, rather than a disability. As diabetes educators' favorite turn of phrase went, "people with a slight ailment become healthier than those who are never ill" (*ichibyō sokusai*). That is to say, disease also makes you healthy. Forget that disability talk! "You see, patients don't like the word disability (*shōgai*) and handicap (*furi*). They come here to stay healthy..." Dr. Komata, a reticent doctor in the ward told me once after my apparently fruitless attempts to interrogate him about disabled patients in the ward. "I mean, they want to keep up a healthy life, that's what they come for. I show them the likely complications, because I want them to see what they work on [to prevent]. And then they, too, want to see these hazards. But I don't want to use the word 'disability,' because it sounds like something irreversible, doesn't it?"<sup>59</sup>

While the juridical and scientific definitions of disability were avoided, or even formally rejected in daily contacts with patients, they were nevertheless inscribed into the practices of diabetes treatment by depicting a terrible future with severe complications. This bizarre symbiosis of law and the local ideas of good patient care formed new patterns of intervention, although people rarely talked about disability in a legal or medical sense. They talked about yoghurt, the ideal injection sites on the body, or test results that helped to make sense of a multiplicity of categories.

## 6. Internal secretions

*Each network makes a whole world for itself, a world whose inside is nothing but the internal secretions of those who elaborate it.*

—Bruno Latour

In the daily acts of coming to terms with diabetes several things were linked together from legal categories of disability through worrying wives and clinical trial groups to red blood cells. Those who tried to avoid long-term complications of elevated sugar levels in the blood must therefore have learnt to be affected by the internal secretions of insulin and other hormones in their bodies in entirely novel ways. Appreciating food revealed the routine calculations of carbohydrates and a concern for daily glucose fluctuations. The search for complications in a series of diagnostic tests, on the other hand, performed the metabolic disorder of enduring sugar excess in the body and its dreadful consequences over the years. With eating and diagnosing in the hospital, the implicit principles of the metabolism had been thus introduced into the body. Paraphrasing Marilyn Strathern, the (cultural) form that metabolism at the clinic was tantamount to a theory of social action.

As an implemented or acted upon theory, we might equally well call it a practice of social action. Indeed, these constructs become visible on occasions when people do not simply wish to reflect on the causes of action but to create the conditions for fresh actions. Actions are known by their effects and outcomes. These constructs are thus also a theory of practice of production. (Strathern 1988: 16)

Exploring the interdependence of practices and ideas is a common theoretical concern of anthropology sharing a deep sense of interest with studies of science and technology (Evans-Pritchard 1937; Fleck 1979 [1935];

Malinowski 1948, etc.).<sup>60</sup>

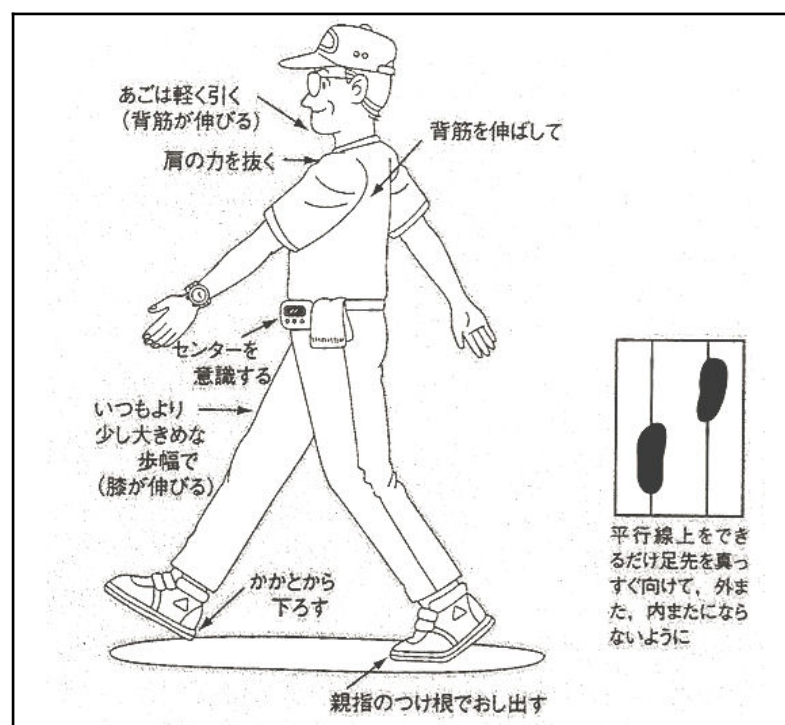
Contrary to many medical anthropological accounts of the multiplicity of suffering versus a homogeneous medical gaze (Kleinman et al. 1997; Ukigaya 2014), or that of many historians of science about the diverse ways biomedicine is produced in laboratories and scientific debates predicated on the silence of anonymous bodies (Reiser 1993; Rosenberg 2002), I argued that such knowledges and experiences *become plural and differentiated in the acts of relatedness*. In other words, they are co-produced.

In the Suzuran Center, diabetes was defined as a metabolic disorder characterized by inadequate secretion and/or utilization of insulin. People who had diabetes were told to be unable to metabolize a part of the food they ate. Some may argue that this biomedical explanation stands in contrast to humoral concepts of *balance* found in various "folk belief systems" (see e.g. Cohn 1997), whereas others describe the metabolism as a narrative model of constructing a "pathologized life" through shared cultural ideals of *control* (e.g. Loewe et al. 1998; Pendry 2003: 149–153). It is not enough, however, to substitute one idea for another, to show that balance is essentially a symbolic representation, while control is a discourse of power. What is more striking from an ethnographic point of view is how such different ideas are linked up and come to stand for each other in clinical settings.

Patients, doctors, bodies and technologies accomplish in practice what anthropologists take for granted. While nurses and doctors were seeking in the metabolism a primal model for establishing and treating disease, patients and their families were hoping to act upon it in a way that reduced their suffering and the risk of further ailments. So, it was intrinsically useful not only as a scientific paradigm<sup>61</sup>, but also by virtue of the effect it had on human lives: it was an implicit principle of imitating the daily routines of diabetes

patients. It imposed regular order while it was inscribed with irregular activities.

The idea that I have begun to develop is that disease depends on the practices of differentiation in the institution of the clinic. The differences between modes of measuring glucose levels, between nutrition and food, or between disability and health were simultaneously individual and collective. Doing disease in the hospital meant following the metabolism, which was a question of coming to terms with and respecting its daily rhythm embedded in the routines of clinical practice.



**FIGURE 2-2** Learning to walk

Explanation of the scientifically ideal walking style in an academic journal. (Source: 青柳 2003:270)

The schedule of diabetes education was based on so-called clinical paths in which the seemingly incommensurable levels of diagnostic tests, meals,

insulin shots and diabetes classes were located on the very same diagram making their relations upon each other practically inevitable. In the middle range of one such chart there was a row tagged "exercise" with an image of a walking man (for a similiary, but not identical image, see *Figure 2-2*). The caption said "Walk at your pace!" (*Jibun no pēsu de arukimashōi!*) Rather than a force of theoretical generalization, the diagram of the clinical path became a part of medical practice in which differences between the singular and the plural could imitate and stimulate each other.

The visual artificiality of the metabolism allowed for the correspondence of selves and others in time: everyday cycles as a collective experience of food and the linear knowledge of ageing in the form of diagnostic tests. In doing so, it linked up one's own pace of walking with other people's eating habits and complications, and with yet other routines that became articulated upon the internal secretion of insulin and the changes of blood sugar. The singular was mimicking the general, and vice versa on the normalized geometry of the clinical path. It was through such tools of everyday clinical routine that the differences between experiences and knowledge were established practically. By imitating it in charts, algorithms and medical technologies, its daily changes and long-term effects gave the metabolism order and formed an embodied logic around it.

This is how the Japanese philosopher Ichikawa Hiroshi criticizes the concept of 'metabolism' from a phenomenological perspective in the introduction to "The Body as Spirit" (『精神としての身体』): "The human body is generally regarded as "a material something with various physiological functions, such as *metabolism*, that *becomes a tool for the spirit in acting upon a real world*, sometimes resisting, and at other times troubling, the spirit, or being dominated by it". However, from a phenomenological

perspective, he continues, "our concrete life in its great part is spent within the structure which cannot be reduced either to the spirit or to the body" (Ichikawa 1975; cited in Nagatomo 1992: 4–5, emphasis added).

Although at certain points I have referred to embodiment, the reader should be aware by now that this is done not in a cognitive or phenomenological sense of the word. The focus is rather on *disease as practice*, and by that I mean the ways of knowing how different parts of the body are being related and how, along the way, such differences physically stimulate one to know more about oneself and others. A sensing body is certainly indispensable to experience diabetes. But it is not sufficient. You need more things and also more people: medical records, nurses, other patients, scientific articles in the hospital library and pamphlets issued by pharmaceutical companies spread over the shelves in the inpatient lounge. You need, not least, hospitals where the metabolizing body merges with the arrangements of its understanding and knowing becomes a way of relating to it.

## CHAPTER THREE

### **Of Mundane Technologies and Sensing Bodies**

*in which relations of disease unfold, and diabetes is embodied technologically*

*Attending to the whole person requires its own technology, its own artifacts.*

—Marilyn Strathern

Having looked at the *emplacement* of diabetes care (Chapter 1), and at the different ways of *encountering* with high glucose levels in the blood (Chapter 2), here I will focus on the *relations* of disease that unfold in the material adjustment of values and practices discussed in the previous chapters. I will show the different ways of objectifying and appreciating (Bourdieu 1977: 86) the symptoms of diabetes by doctors, patients, devices, bodies and user-consumers of medicine in general. To locate the power of such symptoms, I trace the emergence of disease through three different procedures of managing diabetes: measuring blood glucose levels, detecting diabetic complications on CT scans and slides of blood viscosity, and, finally, the interweaving levels of choosing among a wide range of available medications.

None of these diagnostic and treatment strategies rely exclusively on the biological processes revealed in laboratories and medical textbooks (and then, in addition, by sociologies of scientific knowledge), nor do they conceal the perspectives and experiences of patients (waiting to be unbracketed by medical anthropologists). At stake, rather, is the sensate bodies that become capable of feeling and appreciating sugar in the blood and ageing in Japan in new ways, and the continuous negotiations of chronic disease through the interaction of human senses and medical technologies. How do technologies



engage in the embodied activity of knowing disease in everyday practicalities of medicine? How do such techno-cultural interactions reorganize collectives and mediate new identities *along* the medical sciences? These are the main issues I tackle in this chapter.

## 1. Medical technologies in practice

Diagnostic tools, imaging modalities and drug therapies are central in the organization of most medical settings in contemporary Japan. Patients enter the health care system through X-ray pictures, sphygmomanometers (blood pressure meter), and antibiotics, to mention just a random few of the multitude of artifacts indispensable for most basic medical treatment. Interestingly enough, while anthropological (Lock 2002), economic (Hisashige 1996) and STS (Low et al. 1999) accounts all agree that Japanese people have an ambiguous attitude toward new innovations in health care,<sup>62</sup> the country was by far the world leader in the diffusion of medical technologies at the time of my research.<sup>6364</sup> Quantities and qualities don't seem to match up in any easy way. But while there a lot of debate about the social *implementation* and *assessment* of culturally paradigmatic innovations in Japan, there is much less written about how people *appropriate* objects of medicine *tout ensemble* in their everyday practices of coping with chronic disease.<sup>65</sup> Once such technologies are acted out on human bodies, a variety of patterns emerge, which have the potential to redefine forms and meanings of suffering as well as the scientific categories of disease.

*How, then, do medical technologies and suffering patients come affect each other?*

Some sociologists and anthropologists find the answer to this question in the generation and diffusion of social meanings. Biomedical imaging

modalities, we are told, *represent* differences and similarities; global inequalities, national ideologies and social roles are *constructed* through genetic and other diagnostic techniques (e.g. Matsuoka 2014; Nelson and Robinson 2014). Or, take for example the design of drug trials that, we are told, inform "the science-based way of life of our society" (Collins and Pinch 2005: 205). Technologies, here, are portrayed as the surface of the seemingly omnipresent process called medicalization.<sup>66</sup>

Others point to the impact of technologies per se rather than digging too deep through social dynamics. Here, it is the continual improvement of medical tools and devices that generate kinship, community and other forms of social life by *reducing* rich human experiences of illness into physical signs of disease. Or what is more, they *determine* our categories of gender and race (e.g. Inhorn 2015; Tsai 2010). Medicalization—from the other way around.<sup>67</sup>

Of course, professionals and patients also have to deal with the issue of how medical artifacts and disease attend to each other. And they do it in their own ways, if not exclusively in academic papers or in ethical debates on the editorial pages of national news dailies, then in their daily routines of medical practice. It is there, in those mundane encounters with stethoscopes and ultrasound pictures, that an ethnographic account of disease can possibly begin. This approach may be called *technologies-in-practice*, a concept introduced by social scientists of medicine Marc Berg and Stefan Timmermans, who stress the importance of mundane artifacts.

Technology-in-practice leads thus to a broad definition of technologies, including the entire gamut of mundane to sophisticated technologies, drugs, and even managerial instruments such as patient records. Actually, in this approach it is difficult to single out one technology as an isolated device because technologies are embedded in relations of other tools, practices,

groups, professionals, and patients and it is through their location in these heterogeneous networks that treatment, or any other action, is possible in health care. (Timmermans and Berg 2003: 104)

An open mind toward the objects of medicine is, not incidentally, makes a fruitful dialogue between medical anthropologists and STS scholars possible.<sup>68</sup> From the latter's point of view, anthropologists tend to ignore the clinical production of medical categories in favor of examining the practices and intersubjective milieus in which these categories are experienced (Cambrosio et al. 2000b: 3). They may be right. Yet, the important question of how science makes social sense may obscure other significant interferences between the personal, the physical and the biological in medical practice. The proliferation of medical technologies beyond the hospital and the changing relationship between patients and medical professionals in Japan have made such ways of portraying medical knowledge more problematic than ever.

My intention is to challenge such views of the incommensurable worlds of suffering and knowledge, and follow certain artifacts in the clinical intervention of diabetes that point to general facts and particular values at their intersections. In this chapter, I examine the complex relations of knowing disease by taking medical technologies and their users seriously and show how they mediate between scientific and human domains. To do so, I try to situate my ethnography between the social monster of medicalization and the fragmented pluralism of illness narratives by linking them to some important STS questions. My suggestion is that we trace the mundane objects of medicine as they come "to organize the relation between what is inscribed in them and what can/could/should/ be pre-inscribed in the users" (Latour 1992: 236).

There is an anthropological answer to the question of *how do medical*

*technologies and suffering patients count for each other?* It tells how different diagnostic and therapeutic devices and the multiple voices of disease are drawn together and act both ways. It tells how all this is a practical and local matter.

## **2. Diabetes and some mundane artifacts**

A well-known story about "The Drunken Indian and The Kidney Machine" is a case in point. First, the story revolves around a specific *medical technology*—hemodialysis—used in the treatment of a fairly common chronic condition, the failure of kidneys. Second, it is an *anthropological* story, passed from one anthropologist to another, who put it in writing (Geertz 2000 [1985]).

The narrative is set in the southwestern United States, where dialysis was rather scarce in the early eighties. The old Indian who had been, quite luckily, put on dialysis care was unable to control his drinking habit, a basic criterion for the treatment to be effective *and* ethical. He felt it was his right—as a minority, as a declassed old man, or possibly because of his people's colonial past—to be treated, anyway. The middle-class doctors, on the other hand, assumed that taxpayers' money could have been used for better ends, although their ethical selves and the strict rules of their health care system would not, of course, allow them to refuse his treatment. The Indian's life was extended, and the differences were neither swept away, nor solved until the day of his death.

This is a story about clashing cultural values connected relatively routine technological intervention. The underlying problem with it (if it is a problem at all) is that it doesn't offer an easy social, or ethical conclusion, as Geertz notes cursorily: "The antagonists here, if that's what they were, were not representatives of turned-in social totalities meeting haphazardly along

the edges of their beliefs" (81). Conflicting values seem to be at work as part and parcel of a simple routine of cleansing of one's blood three times a week with a rather costly but common technique.

Hemodialysis is a chronic life-support therapy, in which toxic wastes are eliminated from the blood by a filtration apparatus. It is used to provide an artificial replacement for people whose kidneys fail to do such filtering, for example owing to diabetic complications. The dialysis station was one of the busiest places at the Suzuran Center. It was located in a separate wing of the hospital, because it required additional hygienic precautions. When entering, I had to change my shoes to slippers just like in most Japanese homes or private clinics, and put on a pink gown. Patients did the same before they walked to their beds (no *futons*—this time and this place). The forty beds were almost always in service providing care for hundreds of people from the neighborhood who came here three times a week to spend three to four hours connected to a machine by two giant needles stuck in their arms. Blood flowed out through one of the needles, and traveled through the device so that they could indeed see their own blood being circulated in the transparent plastic tube and then flowing back into their bodies. Most patients tried to pass the time reading, others simply dozed off, and some were eager to make new friends: "The doctor said my blood is thick (*dorodoro*), what do you think?" a patient turned to the bed next to hers pointing at the tall and narrow instrument, and continued in the same breath: "If you ask me, it's rather sweet than thick [laughs]. We have diabetes, after all!"

Dialysis, of course, is not the only technological means of performing the blood that flows through the vessels of diabetes patients, but it is a good example of how undergoing even big and complex medical treatment becomes an everyday matter of making selves in the hospital. From routine

tools to cutting-edge solutions, technologies are important intermediaries in the process of establishing and managing "sweet blood." Some are located at the dialysis station or in the radiology department, and some are found closer to the center of the hospital, or, with increasing frequency, in people's homes.

\*

The advent of new treatments since the beginning of the twentieth century, most notably the discovery of insulin, have transformed the previously fatal disorder of high sugar levels in the blood into a manageable chronic condition. People had to learn not only to inject their own insulin, but to keep their syringes sterile and their needles sharp (with a whetstone). Along with formerly unknown problems of living longer in such a state—lost kidney functions, clogged blood vessels, blindness, stroke, liver disorders, etc.—techniques of controlling and preventing these so-called complications have continued to burgeon. Today, many diabetics in Japan measure their blood-sugar levels several times a day and then adjust insulin dosages to the results. Others need no insulin shots, but nevertheless many of them monitor their glucose along carefully established self-management plans. Self-control has become a critical pillar of treating diabetes mellitus, and most new developments are situated within this technoscientific context. Academic talks and hopes of stem-cell research and transplantation of the pancreatic islets, or the biotech success story of genetically engineered insulin are just as important in the shaping of diabetes today as the daily use of various new pills, blood sugar tests, sweeteners, specially-designed shoes or calorie-calculating softwares and applications. The health logbook and the insulin pump are two of the abounding examples that show such links between

disease, scientific facts and lives in the making.

*The health logbook.* A physician in Tokyo drew my attention to the official name of the widely used diabetes management diary (*tōnyōbyō kenkō techō*).<sup>69</sup> This little notebook contains the result of the monthly routine tests, such as cholesterol levels, blood pressure, and glucose levels. You may pick it up at the local drugstore, health centers or the waiting room of outpatient clinics. In the mid-nineties, there was a heated debate between physicians and bureaucrats from the Ministry of Welfare over the naming of this book. The latter argued that it must include "health" in its title, so that the value of well-being is clearly indicated for the users. They keep it for their own *healthy lives*. Endocrinologists, on the other hand, claimed the facts involved: sugar in the blood. They insisted on the use of the word diabetes (*tōnyōbyō*) in the heading of the book, an expression that contains the Japanese suffix for 'disease' (*byō*). The title of the diary thus became "diabetes disease-health logbook" (*tōnyōbyō kenkō techō*). Adding things up is certainly a way of overcoming complexity. We can see that disease and health are not two sides of the same coin. When it comes to coping with diabetes in Japan, they are added up to form the cover of the "Bible of diabetes patients," as my doctor friend in Tokyo referred to the little notebook.

It is this liminal state of connecting moral selves and scientific objects, and the multiple ways it is mediated by the interaction between medical artifacts, humans, and bodies that drives my interest here. Rather than simply being implemented, such techniques and devices are perpetuated and acted upon in the daily practices of managing glucose levels.

*The insulin pump.* Miura-san is a businessman in his sixties. He uses an insulin pump (CSII) that delivers insulin continuously to his body through fine tubing and a needle that is inserted just under his skin. The small device

he wears on his belt administers the amount of insulin automatically between meals (basal rate), but he has to set the program before each meal to match the amount of insulin to the food he is to eat (bolus dose). It is this so called basal/bolus system that allows him to carry on with his hectic working schedules. "I had been taking premixed insulin twice daily. I had to keep a regular schedule of eating, so that the shots wouldn't cause hypoglycemia.<sup>70</sup> The work of insulin in my body took control over my whole life. But with CSII it is the other way around: the device adjusts the doses of insulin to my life" (Japanese Association for Diabetes Education and Care 2002: 214–226). Miura-san feels his life is back in order now. He enjoys himself again without the constraints of injecting insulin twice a day. He can eat whenever he likes; it's a matter of a little tinkering. His social self, his appetite and his diagnosis are accomplished technologically. He may go out with his friends again, and tell them, or his doctor about the sensation of low levels of sugar in his blood. It is he, after all, who changes those levels. Or the parameters, at least.

Of no surprise to anthropologists, human lives are hardly extricable from the social lives of particular things (Appadurai 1986). Neither are categories and meanings (Daston 2004; Henare et al. 2007). As I mentioned, diabetes is a complex disease. Things, narratives and scientific categories abound. Simple technologies and a collective of physicians and patients, however, can turn this complexity into routine practices. If I am to explore the consequences of the argument that processes of linking the singular and general are located in practicalities (as outlined in outlined in Chapter 1), I have to return to the places where "big issues" are ethnographically visible and empirically most compelling.<sup>71</sup> Slightly altering Bruno Latour's famous motto, I will focus on technologies in action. At the Suzuran Hospital this means "putting technologies on the body."



### 3. *Mi ni tsukeru*

The idea that technologies and categories are entangled was embedded (or should I say embodied?) in every level of the organization of diabetes care and on every floor of the hospital.

On the third floor, there were walking machines set up for inpatients whose treatment required daily exercise. The instructor explained the nitty-gritty of walking therapy. There were several things the person with diabetes had to remember before he started even such a simple act as walking. A shoe, for example, that doesn't chafe the foot, because diabetic patients may develop ulcers from the tiniest scars. They also needed to carry a glucose tab or some other fast-acting sugar that may be necessary if poorly controlled sugar levels fall too low during exercise. And if all this was not enough for a short walk on a machine, it was also recommended that "while walking you wear a pedometer" (*Manpokei wo mi ni tsukete aruku*).

A pedometer is a tiny little device that records the number of steps during walking based on the body's movement. Given that one attaches it to her belt in a horizontal position and she tries to acquire a sense of walking that makes the sensor read each and every step. "So," the instructor reminded the three women who took the challenge on that day, "try to walk with your hips and knees flexed as much as possible, otherwise the apparatus won't feel your steps." And he demonstrated the movement to the slightly embarrassed women: "Something like this..., let your body feel this way of walking" (*Tadashii arukikata wo mi ni tsukemashō*).

"Putting something on the body" (*mi ni tsukeru*) is a crucial way of doing diabetes in Japanese medical settings, although it is virtually never conceptualized as such. As a linguistic term, it encompasses a wide range of meanings that seem to evade any easy translation. It refers literally to the act

of wearing clothes, or putting something—an object—on the body. A pedometer, for example. But in its most common usages at the sites of diabetes care *mi ni tsukeru* becomes a disposition and power to learn, to acquire a skill, to know disease, or walking styles.<sup>72</sup>

*Things and technologies don't make values, things at work on the body do.*

The process of developing a sense of walking with high sugar levels, thus, is not simply the use of pedometers and the perfect shoes. It is through the incorporation of overlapping technological arrangements that the knowing of an enhanced metabolism becomes possible at all.<sup>73</sup> Patients indeed have to put many things on their bodies: skills of guessing calories and dropping glucose levels, habits of living with a threat of complications (*gappeishō no kuse wo mi ni tsukeru*), the shape of the pancreas, the width of vessels, not to mention new lifestyles that have to be acquired most of all. The list is too long to continue.

Following the appropriation of medical technologies keeps the anthropologist in motion, because there are many other interesting things to put on the body on the lower floors of the hospital. Or even in other places further away. A stethoscope, for example, allows physicians to monitor heart and lung sounds of the patient during the monthly check-ups for complications. Wearing it around the neck authorizes one to make an expert diagnosis; yet, in certain situations, it tells about the limitations of the Western doctor when compared to his colleague of Eastern medicine who relies on his bare hands for detecting disease. Importantly, however, there is a tendency to allow patients to move health care back to their home (Pols 2012), and mundane artifacts, like a stethoscope, changes places rather easily. So, alternatively, patients can perform such diagnosis at home by themselves placing it into their own ears to amplify their own heartbeats. They can then

download the sound of a healthy heartbeat from the internet and compare. Lub-dub, lub-dub: that's how it sounds—in a stethoscope, in mp3 format. Back in the clinic, now they have a lot to talk about: "Doctor, I think I have atherosclerosis. You know, I bought this stethoscope and listened to my heartbeat at home, and it sounded like a 'whooosh,' isn't it because of the thickening of my artery?"<sup>74</sup>

Technologies, instruments, and medical images surround the patient from the very first day of treating diabetes. She is expected to acquire the techniques of manipulating such devices, and thus allowing doctors and nurses to have a better grasp of the disease. Therefore, the Japanese term of *mini tsukeru* seems to be equally fundamental—even if unarticulated—to the English one, self-care, which is nevertheless used more conceptually at Japanese sites of health care too.

Technologies do not stand by themselves. They must be appropriated, or rather, *embodied*. When things are put on bodies, they make each other be moved and be affected. Knowing diabetes presumes then that there is an effort to become interested in caring for disease, that there are objects and bodies to make links, *inter-esse* (Despret 2004).

Next, I will look at three different techniques of blood-glucose measurement in detail. All of them help to assess the physical condition of diabetes in different ways: by numbers, pictures and pharmaceuticals. Not only that, they do more in practice. They draw people's attention to their sensing and suffering bodies. The intriguing thing is that in practice such passages connect.

#### 4. Hyperglycemia at your fingertips

OGTT. Establishing the possibility of diabetes at the Suzuran Center started with a simple blood sugar test performed on every person before being admitted to the treatment, and was repeated at each monthly visit to the clinic afterwards. The so-called oral glucose tolerance test (OGTT) is a laboratory procedure that measures the amount of glucose (sugar) in the blood. A 5ml sample was drawn from the patient before and after drinking a special sugar drink. The blood samples were carried to a laboratory where they were centrifuged and processed. More than 126mg glucose in the plasma before, and more than 200mg two hours after drinking the beverage was regarded as high and called hyperglycemia (*kōkettō*). Strictly speaking, it was not a disease yet, but a sign of metabolic disorder, that is, diabetes.<sup>75</sup> Most people at this stage and at this clinic were recommended a ten-day to two-weeks stay in the hospital for a general checkup and a self-management training program to stabilize their glucose levels. The hundred odd pages long *Manual* they received upon hospitalization went on to describe the main causes of the disorder derived from the laboratory results. Either the pancreas cannot produce enough insulin (type 1 diabetes), or the body is unable to use it effectively (type 2 diabetes). Possibilities for disease were thus established early in the treatment process, but not yet appreciated in practice.

Numbers are powerful, and too much sugar in the blood is a sign of something going wrong in the body. Numbers are even more powerful however when they are many and have a history (see *Box 3-1*). Doctors, who know very well how important trajectories are in chronic illnesses, would like to have more and more results. They want to see the *process* of disease. Of course, it was quite unfeasible to ask patients to come to do a test every single day, but fortunately there was another method that showed those trajectories more easily: the *hemoglobin A<sub>1</sub>C (HbA<sub>1</sub>C) test*.

### Box 3-1 The power of numbers

#### Interview with Hiroyuki Kano, computer expert, active member of Aum Shinrikyo

MURAKAMI: *So it was very important for you to be able to measure the amounts of the force or to be able to map it visually.*

HIROYUKI KANO: That's right. If you systematize things this way, your arguments will ring true. In this sense modern science is an amazing system. In Aum, too, there are many valuable parts. I want the meat of it to remain. Aum's finished as a religion. It has to be theoretized as a natural science. I'm not much interested in things that can't be measured scientifically. What cannot be measured has no persuasive power, so whatever value it might have can't be transmitted to other people. If things that can't be measured acquire power, you end up with something like Aum. If you're able to measure things, you can exclude the potential danger.

MURAKAMI: *Okay, but how much reality would these measurements have? And wouldn't they differ depending on your viewpoint? There's also the danger that data could be manipulated. You'd have to decide at what point your measurements are sufficient, not to mention the question of the reliability of the instruments used to do the measuring.*

HIROYUKI KANO: As long as the statistical structure you use is the same as that used in medical science, then it's okay. These symptoms mean this, this is how you treat them, that sort of thing.

MURAKAMI: *I don't imagine you read novels.*

HIROYUKI KANO: Three pages is about the most I can manage before I give up.

MURAKAMI: *Since I'm a novelist I'm the opposite—I believe that what's most important is what cannot be measured. I'm not denying your way of thinking, but the greater part of people's lives consists of things that are unmeasurable, and trying to change all these to something measurable is realistically impossible.*

HIROYUKI KANO: True. It's not that I believe these things that can't be measured are worthless, it's just that the world seems filled with unnecessary suffering. And the causes of suffering are increasing—uncontrollable desires are causing people to suffer. The appetite for food, for instance, or sex.

(Excerpt from *Underground* by Murakami Haruki, 1997, pp.255-6)

*HbA<sub>1c</sub>* test. In this case, the number of glucose molecules attached to hemoglobin (a substance in red blood cells) was measured—in the same laboratory, on the same blood sample, with different machines. The chemical reaction here took advantage of the lifecycle of red blood cells. Although being constantly replaced, single cells live for three to four months. That is to say, measuring attached glucose in a current blood sample, average blood sugar levels over the previous two to three months could be determined. These numbers, more than the disease, stood for the rights and wrongs of self-control. The goal was set at 6%, and those with more than 8% were warned to

be in a great risk of developing serious complications.

The new test also told about patients' characters. "They come to see me and tell me what happened to them last month," an internist said in an interview, "All kinds of stories. But while listening to them, I look at their HbA<sub>1</sub>C results, and I know they don't always tell me the truth. It's all there in the numbers! But, you know, I avoid confronting them with numbers. They would be furious or stressed, and it wouldn't help the treatment, anyway."<sup>76</sup>

\*

SMBG. Yet, there were many others—doctors, nurses, diabetes educators—who truly enjoyed confronting patients' stories with their numbers. And they could actually do so, because there was a third way of measuring blood sugar, this time by patients themselves. The routine self-monitoring of blood glucose (SMBG, *jiko kettō sokutei*), which had been crucial to the treatment of insulin dependent-diabetics (type 1) for more than a decade was recommended for non-insulin dependent patients (type 2) too at the Suzuran Center, in order to clarify the goals of self-control, and measure the effectiveness of the therapy (see *Appendix 3-2*).

Self-monitoring is based on a simple portable device that measures the level of sugar in the blood. The sample is obtained by pricking a finger with a specially designed tiny needle, also called a lancet (see *Figure 3-1*). The use of the meter itself is a relatively simple process, the technique of which was mastered by most patients in one to three individual training sessions by first following the nurse's instructions, and later by memorizing a 17-point checklist from hand washing to the correct disposal of the needles (see *Appendix 3-3*).

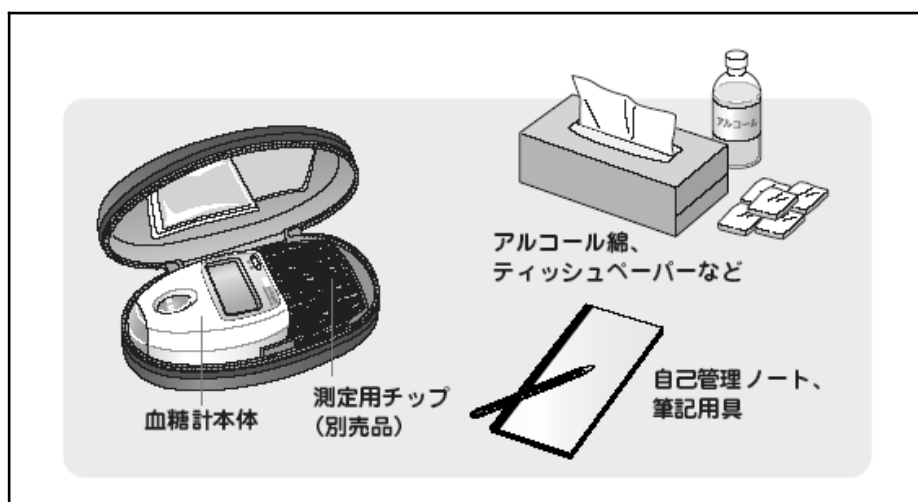


FIGURE 3-1 Image of tools for blood glucose self-monitoring

Murakawa-san had been hospitalized two days before the first training session, and she looked rather enthusiastic when the nurse put the device on the table.<sup>77</sup> Puzzled by the thought of constant medical attendance, which seemed to contradict with her busy working schedule, she was nevertheless determined to take control of her life. After all, she had been doing it for most of the twenty-odd years following an early divorce and long years of struggling with tuberculosis in her thirties. She was working in a small company as an accountant close to retirement, when she found out she had type 2 diabetes. More than frightened, she seemed to be rather enthusiastic about fighting the disease in her body. This seemed to be quite reasonable, according to her doctor. It just takes measuring glucose three times a day, after all.

Following an explanation of the dreadful poster about used needles on the wall, the nurse started to lay out the tiny pieces of the device on the table like a magician who shows how the tricks are going to be performed—step by step. Now, watch my hands, no cheating! Following a short demonstration,

Murakawasan was at last allowed to try to piece together the tube and the spring-loaded lancet. Next, she pressed the button to release the lancet, mimicking the movements of the nurse on the other side of the table. I could catch the smile on her lips when she finally beheld the long-expected drop of blood forming on her fingertip. The drop has almost immediately transformed itself into a sample having been placed on a disposable test strip with a biosensor. The latter was coated with an enzyme called glucose oxidase that combined with sugar in her blood activating a chemical reaction. The strip was then placed into the meter, which digitized the result in front of our eyes. After ten long seconds with bated breath, the meter displayed the glucose level as a digital number: 253 [mg/dl].

"It's still too high," the nurse added, "but it will go much lower after a few days on hospital diet." Murakawa-san, however, did not seem to care too much about the result itself. She was simply glad to perform the task of measuring her glucose level, which apparently gave new meaning to the disease hidden deep inside her body. She started to record the result in a small note book (*jiko kanri nōto*), while the nurse was explaining the meaning of this very first number supposedly followed by thousands of others in the rest of Murakawa-san's life.

***Nurse:** It is usually between 100 and 200, but sometimes your glucose level can go very low or very high. These conditions are called hypoglycemia and hyperglycemia, and you'll surely learn a lot more about them in the class tomorrow. Anyway, what's important for now is that this meter can display numbers from 20 to 600. If you get a reading higher or lower than this range, that would indicate trouble with your meter. In that case, you should consult your doctor immediately.*

***Murakawa-san:** So what if my sugar level was really less than 20 or more than 600? How can I see it?*



*Nurse: No, that's very unlikely. Even if it was, you would faint and couldn't read the screen, so don't worry.<sup>78</sup>*

It's probably not too much to say that for Murakawa-san a new life has begun that day—a life between 20 and 600.

To be sure, I am not trying to reiterate the well-known reductionist narrative by saying that the device flattened Murakawasan's rich subjective personality to objective numbers on the screen. There are other things and other people along the way that, for better or worse, follow from those numbers.

\*

The use of glucose meter was almost mandatory at Suzuran. Devices were provided for free by their makers in an attempt to gain potential lifetime consumers of the monthly package of lancets and test strips (which are compatible, needless to say, only with meters of the same maker). Once patients were through the technical rite of passage in the first or second day of the training program, they were called to the nurse station three times a day before meals to perform self-monitoring in groups of four to six under the supervision of two nurses. Beginners and experienced users sat next to each other waiting for numbers that told them exactly what they did right, what went wrong during the last six hours, and what they should do next to compensate for any irregularity. They discussed their results and evaluated each other with growing expertise. In the course of time beginners have joined these lively debates as they gradually "put the meaning of numbers on their bodies."

*Fukuda-san: 210.... What the hell? [Nande sa?]*

*Muraki-san: Have you slept?*

*Fukuda-san: No, I haven't. I'm a little dizzy, actually.*

*Muraki-san: What did you eat for breakfast?*

*Fukuda-san: Nothing special... the same as you and the others.*

*Muraki-san: Maybe, it's because your family is coming [today]...?*

*Fukuda-san: Maybe... It's been in the 100s for weeks now... Maybe I am too stressed out. I thought it [the blood glucose level] had nothing to do with chatting. But I heard some weird stories tonight in the room that made me excited... Put your hands here [on my wrist]. See? My hands are trembling.<sup>79</sup>*

Fukuda-san probably felt exhausted and anxious by the thought of her visiting family. No wonder. Her daughter kicked up a row every time she appeared in the hospital complaining for problems with the air conditioning in the room, or her mother's strict diet. But despite her own sensation of trembling hands, the old woman asked the nurse for another explanation, just in case. "You probably had a snack after breakfast, didn't you?" the nurse told off the woman, and Fukuda-san was advised to leave some of the lunch on the plate, and return one hour later to check her glucose level again.

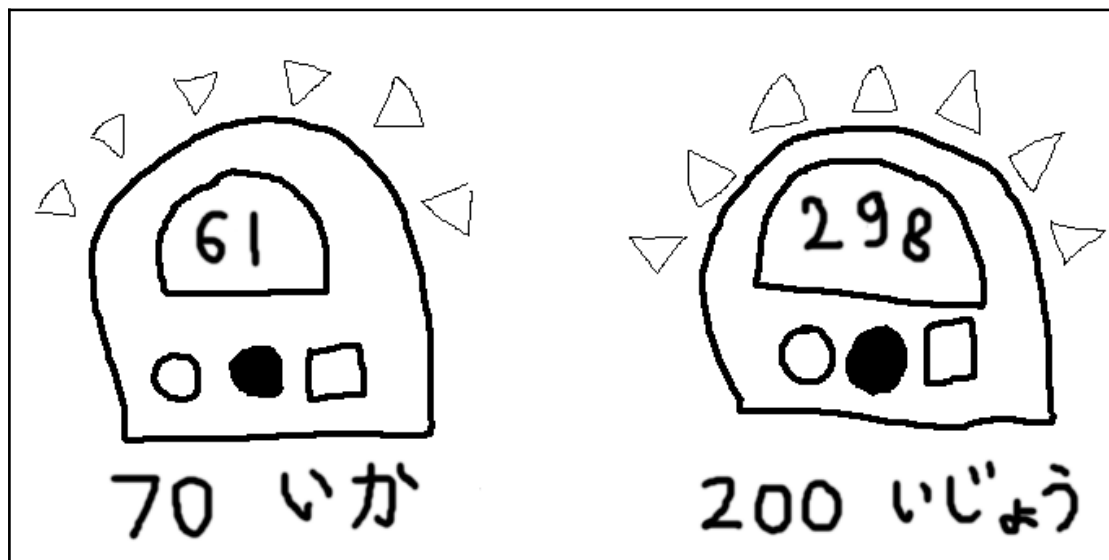
Monitoring blood sugar levels is another means of engaging people with their own bodies. Patients are trained not simply in the skills of measurement, but also to activate their senses and experience the disease again and again. In such a collective of blood sugar measuring patients learn to compare formally neglected reactions to high and low glucose levels. Moreover, they record all these changes in a tiny notebook—or, increasingly these days, to mobile phone applications—in order either to interpret them themselves, or to show them to doctors who would explain them from other angles.

These mundane steps of rendering body and instrument compatible necessarily involve many intangible exchanges with various people, professionals as well as other patients and family members. In diabetic self-care, sensations of good and bad conditions attended with the patient's body are always already modes of attending to the bodies of others in the room, in the family, in the support group, and in the wider society. *How does the stress of a family visit or the morning dizziness translate into glucose levels? Is this the same dizziness as in the textbook? Is it different from Muraki-san who has frequent hypoglycemic attacks during the night?* The understanding of the values of blood sugar lead through the intermediation of self and other, both deeply engaged with "feeling"—or, in other words, knowing—diabetes. Patients are listened to, to make the machine know the disease. And patients, too, listen; they listen to nurses, machines, and well, to their senses.

Some of them reached a level of perfection which allowed them to experience symptoms other than those listed in the textbooks of diabetes. Tamura-san, a woman in her sixties who had been taking daily injections of insulin most of her life, told me about a mysterious back pain every time her blood sugar fell below 70mg/dl—incidentally the pathological threshold of low glucose level.<sup>80</sup> It is this shift of scientific objectification from the laboratory to the everyday life of lay experts, more precisely to the attending body of the patient, which is a case in point in the articulation of selves and others in medicine today.

There were many people of course who could not achieve such a level of sensitivity. Those, for example, who had developed neuropathy in their limbs, or lost their vision, or yet others who could not (or did not want to) prick their fingers three times a day. An old woman at Suzuran was too embarrassed to admit that she was unable to read the instructions and the textbook.<sup>81</sup> I

realized it when I tried to explain her the steps of self-monitoring written in a manual. Being a young schoolgirl during the last years of the war, the woman told me, she had never managed to acquire the skills to read the more difficult Chinese kanji characters. I couldn't help to point out this misunderstanding to the nurse that evening. The following day she prepared a personal guide with only pictures and simple Japanese hiragana characters (see *Figure 3-2*). But in spite of all her efforts, the old woman never really became familiar with using the glucose meter.



**FIGURE 3-2** Reading the senses

Hand-written manual prepared by a nurse at the Suzuran Center for an elderly patient (Author's sketch from fieldwork notes)

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In current Japanese treatment practices of diabetes, the goal is to maintain blood glucose levels as close to normal and as safely as possible, mostly with intensive insulin therapy. For such a tight control the ability to

feel the difference between plummeting and elevated glucose levels is a great advantage. So those who do not have this ability may enter programs to teach them how to do this. Such differences signal that inhabiting a metabolic body with a sensing self is not necessarily self-evident or straightforward. Bodily self-awareness is not something that arises naturally before it is eroded by a medicine that doesn't respect it. It may be hard or impossible to achieve.

The attempts to raise body awareness are important to the topic of this chapter in, at least, two ways. First, measuring devices are used, among other things, to train inner sensitivity. So instead of assuming that there is a contrast between sensing from the inside and measuring externally, these programs tell people to measure blood sugar levels very frequently, and to add up numbers and feelings. Second, in these programs the body is not forced back on its own resources, as if it somehow had to learn how to feel in total isolation. Instead, people are advised to keep better track of what they do and of how this relates to their changing blood sugar. They are asked to keep short diaries in order to learn to see, or even to make the connection between their insulin dose, the food they eat, their exercise, and how they feel. And then they are advised to check the latter by measuring their glucose levels again.

Tight regulation thus depends not just on measuring once or twice, but on the practice of daily self-monitoring. This requires certain changes in the ways medicine is delivered, most importantly the move from the hospital to home, and from the laboratory to the shelf of the drug store. Medical technologies and home diagnostic tests above all, are not administered only by states and scientific laboratories, but became commodities that sell possible lifestyles. The very treatment practices that demand tight regulation emerged as a practical possibility since patients have become able to measure their blood sugar at home, in work, school, on the road, or even in a nursery.

Several times a day, once or twice a week, during the night, between legs of a journey, literally anytime.

So, thanks to the portable glucose meter and its users, calculating risk does not stop at the hospital doors. As an article in *Asahi Shimbun* reveals, those too "who are at high-risk of diabetes (*yobigun*; prediabetics) may improve their condition by daily glucose measurement" (Asahi Shimbun 2004). "Improvement" here points back to the lab, to the HbA<sub>1c</sub> test results that get closer to normal rather than decline toward diabetic levels in people who perform SMBG once a day. That is, monitoring, here, is a form of preventing diabetes itself. So measuring sometimes comes first, *before* disease. Because, if there is disease it must be prevented in the first place. Risk, prevention and improvement keep resurfacing in multiple ways in the continuous articulation of diabetes in time.

## 5. Imaging fat and thick blood

But what about people who are already diabetic? What do *they* prevent? It is certainly not disease, but the death from disease. It's called "diabetic complications" in the literature, and, as several prospective clinical trials showed, tight control—made possible by SMBG—is necessary to reduce such long-term threats of diabetes (see. e.g. Ohkubo et al. 1995).

A second moment in the negotiation of boundaries between health and disease is the constant wrestling with issues of responsibility and compliance in the prevention of lifetime handicaps, such as blindness, limb amputation or end-stage renal disease. As Chris Feudtner, a historian of diabetes, observes, the threat of complications is the central motive in current diabetes treatment situating patients in a medically contested field between healthy lifestyles and terminal disabilities: "With a disease's natural history affixed in their minds,

physicians often configure all untoward developments of a patient's health that run counter to the typical natural history as complications while hailing all therapeutically induced improvements in health as medical advancements" (Feudtner 2003: 43).

Like the average Taro in the manga frightened by the grim memory of a wheelchair-bound amputee, patients at Suzuran were eager to understand and reinforce the difference between disabled others and their own disease (see *Figure 3-3*). They wanted objective and scientific proofs that the potential for disability inside their vessels was manageable through an effort to correct blood sugar levels.<sup>82</sup> One way to draw these lines between disease and disability was the mobilization of internal organs to display properties of metabolic disorder and deadly complications in their own right.

Peering into blood vessels of the eye, visceral fat in the abdomen, or mental activity in the brain became routine procedures in the therapeutic intervention of chronic diseases since the 1980s.<sup>83</sup> As in other fields of biomedicine, advances in imaging technologies such as computed tomography (CT), fluorescein angiography or duplex scanning have been central to the massive changes in screening for diabetes complications in Japan (see *Appendix 3-4*). Among the various diagnostic modalities at the Suzuran Diabetes Center, CT scans of the abdomen and microscopic images of blood flow were probably the most commonly employed technologies in the training of patients. It is, therefore, to the constitution of new senses through visual technologies that I now turn.<sup>84</sup>

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FIGURE 3-3 Disabled others and selves

Diabetes patient facing a disabled person (Japanese manga). Source: (Kaku 2000: 52–55).



After the first day of glucose measuring, Murakawa-san was handed a long list of examinations from ophthalmologic tests on her eyes to ultrasounds of the carotid arteries in her neck.<sup>85</sup> I followed her through these examinations, most of which was performed in different corners of the radiology department on the first floor. The first test on the second day was scheduled at 9am: an abdominal scan with computed tomography. While waiting outside the scanning room, she crumpled a paper in her hand with a timetable of the tests and some basic explanation of the results from the previous day: echocardiography and nerve conduction measurement. "What a nice hospital, it's much faster than the annual health check at my company. I like the way they send me to all these tests. I mean, I learn a lot about my body here." Next, she entered the gantry room with the machine, and I accompanied the technicians to the computer console. After changing to a white gown, we saw her through the window glass being asked some questions, then placed on the table and injected a so-called contrast material intravenously that would make the tissues in her abdomen visible on the screen. Then the table moved slowly inside the machine: an X-ray tube that rotated around her body. I stared at the computer screen with the two technicians waiting for the image to crystallize as the data from the X-ray was gathered automatically. In one window on the left, it showed the scanner slicing through the body from head toward the toes. In the other one on the right, cross sections were shown in a rapid sequence. One of the technicians stopped the motion somewhere in the middle of the body to focus on the abdomen and with simple movements and clicking with the mouse he chose and save the part that best showed the healthy proportion of fat and tissue in Murakawa-san's belly.

Computed tomography (CT), sometimes called a CAT scan, is a noninvasive diagnostic procedure in which cross-sectional pictures

(tomographic slides) of the body are made by a combination of X-ray pictures and computer technology. The main advantage of CT techniques is that it shows the three-dimensional shape and exact location of organs, soft tissues, and bones, and, for example, fat in the abdomen. As a group of Japanese researchers have recently revealed, for example, computed cross-sections of the abdomen are convenient means of obtaining information about the risk of diabetes and the distribution of abdominal fat (Nagaretani et al. 2001). Although the image alone does not tell all that much about a patient's likely complications, a closer look at the picture tells a lot *to* the patient: about the fat in the grilled pork he ate the day before, or her chronic tiredness during the last couple of months. It *unveils* feelings and sensations.

Dr. Mihara, the head of the hospital, an extraordinarily energetic physician in his late fifties, used these images frequently to show his patients that they were obese, even if they could not see it in the mirror. "You know, Japanese people get really irritated when you call them obese. It's something really upsetting. And it's kind of easy to get them to move just by showing the layers of fat in their stomach." Endocrinologists are fond of culturalist explanations—at least when they talk to anthropologists. During clinical visits, though, they are more like psychiatrists. They ask simple questions to help patients get through the tough times. A couple of days later, Dr. Mihara described this encounter eloquently at the weekly meeting of the medical staff.

*Dr. Mihara: I want to find the key that opens the door to each patient, one by one. So, I keep asking them about their small pains, their favorite fruits, and their sex lives. Does this middle-aged lady worry about the monthly all-you-can-eat sushi lunch with her girlfriends? Fine, I will show her the [CT] scan of her abdomen and point to the black areas. 'That is your visceral fat, can you see it?' She will immediately understand*

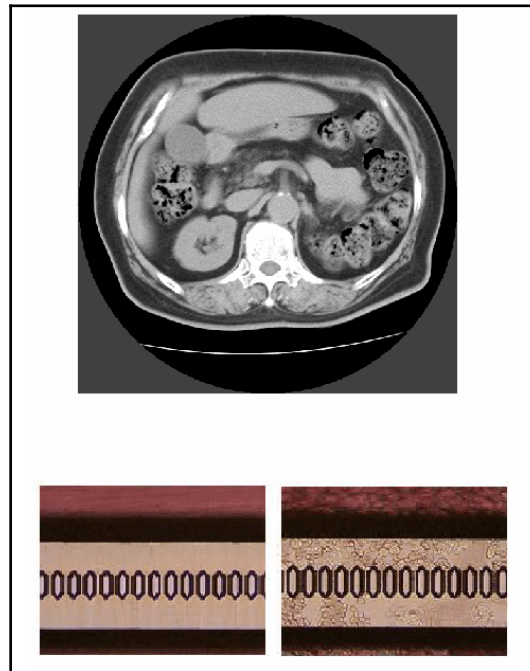
*what I meant by complications. Then I ask her, 'Do you have pain?', and she will answer: 'Yes, actually a little..., a little pain in my stomach. And also, doc, I feel really tired. I know I should lose some weight...'"<sup>86</sup>*

The power of CT scans came from the fact that it was relatively easy for the patients themselves to identify with and interpret them. They could both see and feel their impaired bodies, which enabled them to talk through it. Talk about numb feet, trembling hands, about not enjoying hot-springs anymore, playing gate ball with friends instead, or the stress caused by a visiting family. Images invoked new sensations and provided a common language through which these sensations could be socially shared and compared. During the intensive program of diabetes training, and the subsequent visits to the outpatient clinic and support groups, patients were trying to acquire these new skills of "metabolic sensing." Such novel ways of viewing and feeling hidden impairments of the metabolism provoked the fashioning of objective selves, to use the phrase coined by Joseph Dumit.

Objective-self fashioning is an acknowledgment of local mutations in categories of people highlighting the active and continual process of self-definition and self-participation in that process. Objective self-fashioning is how we take facts about ourselves—about our bodies, minds, capacities, traits, states, limitations, propensities, and so on—that we have read, heard, or otherwise encountered in the world and incorporate them into our lives. (Dumit 2004: 164)

At the Suzuran Center, facts of the metabolism were encountered in the form of scientific and popular images of clotted blood vessels and abdominal fat, among others (see *Figure 3-4*). And these pictures, as Dr. Mihara never forgot to remind his patients, were everywhere: in the radiology department, in comics at the waiting-room, on the walls of the nurse station, or the image

management system that circulated digital records of the diagnoses between wards, departments and countless computers in every corner of the hospital.



**FIGURE 3-4** Imaging diabetes

Medical images of clotted blood vessel. Computed tomography showing visceral fat in the abdomen (above) and blood flow visualized on a micro-channel flow analyzer (below). Sources: Suzuran Center, Department of Radiology (above) and commercial print (below).

\*

In the examination room, PCs were placed on the table so that the sitting patient could see one monitor, which showed his or her comprehensive test results.<sup>87</sup> The doctor was looking at the same screen on a different monitor, and simultaneously another one displaying the general medical records of the patient vis-a-vis. The nurse, sitting behind the physician, was looking at the latter screen while typing the results of the check-up into yet another

computer. Honma-san came to see his doctor before finishing the training program and leaving the hospital. He put his blood glucose record book on the table and sat in front of the patient's monitor. The old man seemed to be in good shape, and his blood sugar levels, he told the physician, had improved considerably during the two-weeks of hospitalization. After examining Honma-san's legs, the doctor pointed at a scar on his left foot.

**Honma-san:** *Oh, well, it's just a bruise. I fell on the ice in my garden, and scratched it a little bit.*

**Internist:** *Hmm, you mean during the past winter? That was more than six months ago... You see, you have to be very careful with these bruises. I tell you why. If your blood sugar level is higher than normal, the blood in your veins becomes thick (doro doro) making it more difficult for nutrients to reach the skin, so your wounds will heal more slowly. The problem is that if it gets seriously infected you may even lose your leg.*

**Honma-san:** *Thick? What do you mean by thick?*

**Internist:** *Yes, your blood becomes thick, sticky, viscous, you know..., well, haven't you heard about these drinks they advertise in the TV that makes your blood smooth (sara sara)?*

**Honma-san:** *No, I don't watch TV anymore...<sup>88</sup>*

To underpin his argument, the physician pointed at the monitor and clicked the mouse a few times opening a window with microscopic slides of flowing blood. Doctors often referred to this real-time visualization of sticky and normal blood. These images of blood flow have become enormously popular in Japan during the three years preceding my research due to the development of a technology called the micro-channel flow analyzer (Seki 2003). The so-called MC-FAN captures blood flow in capillary blood vessels and allows its observation on a video screen under microscope. Microscopic

images of normal (*sara sara*) and viscous (*doro doro*) blood flow soon became icons of popular health literature, not least due to the active involvement of the innovators of this technology (Kikuchi 2001; Kurihara 2002).<sup>89</sup>

Patients with tingling toes or numb feet were shown these slides to distinguish between rheumatism and viscous blood in their veins. Honma-san put on his glasses to take a closer look. Certainly, there was a noticeable difference between the two images: one almost transparent, the other like a muddy smudge. And, of course, he remembered the lectures about foot care, and also Katori-san, an eccentric patient who showed his gangrenous legs to everyone at the ward with an obvious touch of self-pity.

***Honma-san:** Do you think my blood is like that? Oooh, that's too bad. I didn't feel it sticky at all.*

***Internist:** Does your leg hurt?*

***Honma-san:** No, not at all. My toes are tingling (piripiri) though, especially in the morning. I thought it was some kind of rheumatism.<sup>90</sup>*

Honmasan's eyes were still fixed to the images. He seemed to be unable to stop thinking of the muddy smudge in his veins and the tingling sensation of his toes. Before leaving the room, he asked the physician if he could take a copy of the photos with him. He wanted to show them to his son.

\*

In the everyday practice of diabetes control, it is not simply about how biomedicine sees the body. It is about how it makes hidden impairments visible, and how it links scientific knowledge with lay understanding. By

giving objective meaning to blurred vision or a slowly healing wound on the foot, diagnostic images are powerful mappings of the metabolic system that connect kidneys, brain, liver, blood and tissues all over the body. Microscopic slides of "thick blood" and the black visceral fat on a CT scan, in effect, facilitated the negotiation of diabetic selves by linking the objective proof of future handicap with new senses of abdominal pain, excessive thirst or tingling toes.

CT scans of visceral fat are arguably not the most important tools of diabetes diagnosis, but they serve as very effective instruments of making diabetes and its complications visible for patients without much knowledge and interest in their condition. *You see, that's your fat!* The relatively simple act of looking inside one's own abdomen let people discover hidden organs and hitherto unknown bodily signs. The upshot of this technological fashioning of selves is something like this: distinctions between disease and disability are constituted in an accelerated interaction between objective facts of the metabolism, sensing selves of the patient and the presence of handicapped others in the ward. In other words, medical categories—of health, disease and complications—do not precede persons, they both follow from looking at the images of the inner body.

## **6. Pills, needles, choices**

Attending to diabetes, here, follows the selection of medications. How do pills, injections, aerosols, granules, and other pharmaceuticals control blood sugar, stimulate insulin secretion, break down fat cells, or replace hormones?

### Box 3-2 A Hundred sermon, or a Pill?

Excerpt from "A Hundred sermon, or a Pill?" The 'qualitative transformation' of mild diabetes"  
*Nikkei Medical* 2003. Vol.5., p.36.

No medication for "mild diabetes". Such thinking was common sense [among doctors and patients], but now it is time for change. It has been proven, for example, that diabetes, even in its slightest form, is a significant risk factor of atherosclerosis. Therefore, to prevent cardiac infarction and stroke, it is necessary to bring (postprandial) glucose levels under control, from an early stage of the disease. Start your diet and exercise right now, and don't forget to take pills too.

Original: 「軽症糖尿病に薬は要らない」という、これまで常識化していた考え方を改める時がやってきた。たとえ軽度でも、「高血糖」は動脈硬化を引き起こす重要な危険要因であることが分かってきたからだ。心筋梗塞や脳梗塞の予防には、糖尿病発症早期からの食後高血糖の改善が必要だ。食事や運動の指導に経口薬も加えた治療を、今すぐ始めたい。（「百の説法より一粒の薬」『日経メディカル』2003年5月号:36）



## 【特集】軽症糖尿病治療の“質的变化” 百の説法より一粒の薬

「軽症糖尿病に薬は要らない」という、これまで常識化していた考え方を改める時がやってきた。たとえ軽度でも、「高血糖」は動脈硬化を引き起こす重要な危険因子であることが分かってきたからだ。

心筋梗塞や脳梗塞の予防には、糖尿病発症早期からの食後高血糖の改善が必要だ。食事や運動の指導に経口薬も加えた治療を、今すぐ始めたい。

(瀬川 博子、井田 恭子)





In the case of diabetes in Japan, these questions are increasingly formulated in terms of individual differences of consumers and citizens. In such pluralist models of market and welfare, the development of ever better drugs and the health of the nation are located in the recognition of such diversity, and a response to it is created in the form of ethical choices made by individual patients (see *Box 3-2*).<sup>91</sup> Yet in medical settings such choices cut through scientific debates of glucose metabolism, financial interests of drug companies, clinical procedures and people who are looking for diagnosis and treatment at the same time. In the hospital, drugs were not simply selected, or administered into the bloodstream, but, almost needless to say, also put *on* metabolic bodies: first, at regular visits at the outpatient clinic, second, in the weekly lessons on medications at the diabetes class, and third, in the group sessions where patients learned how to inject insulin into designated sites on the body.

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I happened to be there in the examination room at Ikeda-san's first visit in the Suzuran Center.<sup>92</sup> She was a flabby old woman in her late seventies. She had a long history of diabetes and cardiovascular complications but there were other problems with her disease as well. She had been administering insulin to herself for more than a year, as her former doctor had instructed her "to help stimulate the pancreas." In fact, she had been visiting another hospital, but the insulin she was prescribed there caused her frequent attacks of hypoglycemia.<sup>93</sup>

"You know, doctor," she said, "I follow the prescription, I really do. I take my shot every morning before breakfast, not too much, not too little. But then,

around noon, my hands start shaking and sweat breaks out on my body in the weirdest way, and it's..., it's just frightening, you know... Once I even passed out in the supermarket. Oooh, that was so awkward." I don't know what bothered Ikeda-san more, the public embarrassment or the diabetic coma caused by the insulin (or are they two different phenomena, anyway?). Yet, she seemed to be more terrified of the side effects of dropping blood sugar, than any future complications of diabetes.

Next, she pulled out a little device that looked like a pen (and contained her insulin doses), and showed the medication in question to the physician. It was a product called "Novolet N," a pen pre-filled with 2ml (200 units) intermediate acting recombinant insulin—a dose that helped to control Ikeda-san's glucose levels for a month. Or, rather, it didn't. That was actually the problem that brought her to Suzuran Hospital that day. After a quick look at Ikeda-san's leg, the physician proposed a two-week program in the inpatient unit, where she could learn to use insulin in a better way. This was the normal procedure in the hospital: bad glucose control, two weeks hospitalization for training and a general checkup. But not for Ikeda-san.

"No, that's not possible," the patient became anxious for a second, "no, doctor..., my husband lies bedridden at home, he had a stroke, and there's no one else to take care for him. This program is not for me, you see doctor, not now."

After all, the very reason she came to the hospital that day was to quit insulin somehow. This surprised the doctor for a moment, but after a second thought he answered in a firm tone: "OK, so you want tablets, I see. Fine with me. We try some pills, and let's see what happens. If you feel worse, or your numbers get worse, we have to switch back to injections. You see, it is important that you understand this now." Having said so, the doctor turned

back to his computer's keyboard and typed, *Sutāshisu* (Nateglinide), the name of Ikeda-san's new medication that promised to fuel insulin secretion in her body.

\*

Diabetes medications became increasingly common tools of bringing blood sugar under good control. In a country where not so long ago some people with diabetes had to visit the clinic each day for insulin shots, it is now a simple act of prescriptions twice a month—five minutes at the most—to receive one pack from the various types of available pharmaceutical products. The two main categories of diabetes medications are insulin shots and pills, or hypoglycemic agents.

The former is a replacement for the hormone—produced, ideally, in the pancreas—that helps to turn food into energy by encouraging cells to take up sugar in the blood. Those people whose pancreas does not produce this hormone at all (type 1) must inject insulin daily. New versions of analogues, recombinant insulin and the different subcategories of fast and slow acting agents or mixed doses, however, have made it an option for those—and they make up more than 95% of diabetes patients—who do have insulin, but not in sufficient amount, or whose body is less sensitive to it (type 2).

Diabetes pills, on the other hand, do not substitute for insulin, but help bodies to release and use it more effectively. These oral agents also include a wide range of increasingly differentiated therapeutic classes depending on which point they intervene into the complex process of glucose metabolism.

The overabundance of treatment modalities is not only a sign of how chronic diseases become a permanent market of pharmaceutical goods to

choose from, although this is an important topic too.<sup>94</sup> It also shows how such a logic of choice (Mol 2008b)—different but not independent from the market—forms new relations between diabetes medications and their users, in which they come to depend on each other (Hattori In press; Koya 2011; Mohácsi 2011). Pills and injections both help to lower glucose levels, but they do not treat disease in the same way. They instead bring along the reorganization of bodies by allowing social and biological identities include each other in the form of managing diabetes. At the clinic, such inclusions tended to be embodied in a very strict sense of the word.

As patients were often told, it was in/on their bodies that the knowledge of disease and the materiality of the medication intersected. In the lecture room, a comprehensive two-week seminar helped people with diabetes to learn about their disease.<sup>95</sup> The Monday morning class was about "Diabetes Medications." The nurse arrived with an OHP slide that explained the working mechanism of various oral agents in the treatment of diabetes (see *Figure 3-5*). One of them was Amaryl, which stimulates the so-called  $\beta$  cells in the pancreas to release more insulin and helps the rest of the body to use it effectively. The nurse never forgot to remind listeners that it was not a substitute for good nutrition and daily exercise. Those who fail to adjust their habits to the working of medication in their bodies will have to face the dangerous consequences of oscillating glucose levels. It may sound vague and pedagogic, but the map of the human body on the overhead projector showed such connections at a glance: the routes of the drug in the body marked out the links between scientific theories of insulin deficiency and one's daily life of eating with friends or alone, or working overtime rather than following warnings on the prescription. Such links, the OHP explained, had to pass through the pancreas, the liver and fat cells in order to become links at all.

# 薬はどこに効くの？

## ●ビッグアナイド(BG)薬

肝臓がブドウ糖をつくる作用を抑えるのがおもな作用で、一部、筋肉や脂肪細胞などでブドウ糖の利用を高めます。

(商品名：メルピン<sup>®</sup>、グリコラン<sup>®</sup>、メテット<sup>®</sup>、他)

## ●チアゾリジン誘導体

(インスリン抵抗性改善薬)

脂肪細胞に作用して、筋肉や肝臓でのインスリンの作用を高め、糖分を取り込みやすくします。

(商品名：アクトス<sup>®</sup>)

## ●スルホニル尿素(SU)薬

すい臓のβ細胞にはたらいてインスリンを分泌させ、血糖値を下げます。

(商品名：オイグルコン<sup>®</sup>、ダオニール<sup>®</sup>、グリミクロン<sup>®</sup>、他)

## ●フェニールアラニン誘導体

(速効型インスリン分泌促進薬)

すい臓にはたらき、服用直後の短時間のみインスリン分泌を促進し、食後の高血糖を防ぎます。

(商品名：スターシス<sup>®</sup>、ファスティック<sup>®</sup>)

## ●α-グルコシダーゼ阻害薬

(食後過血糖改善薬)

食べた糖質を小腸でブドウ糖に分解・吸収するのを遅らせ、食後の急激な血糖上昇を防ぎます。

(商品名：グルコバイ<sup>®</sup>、ベイスン<sup>®</sup>)

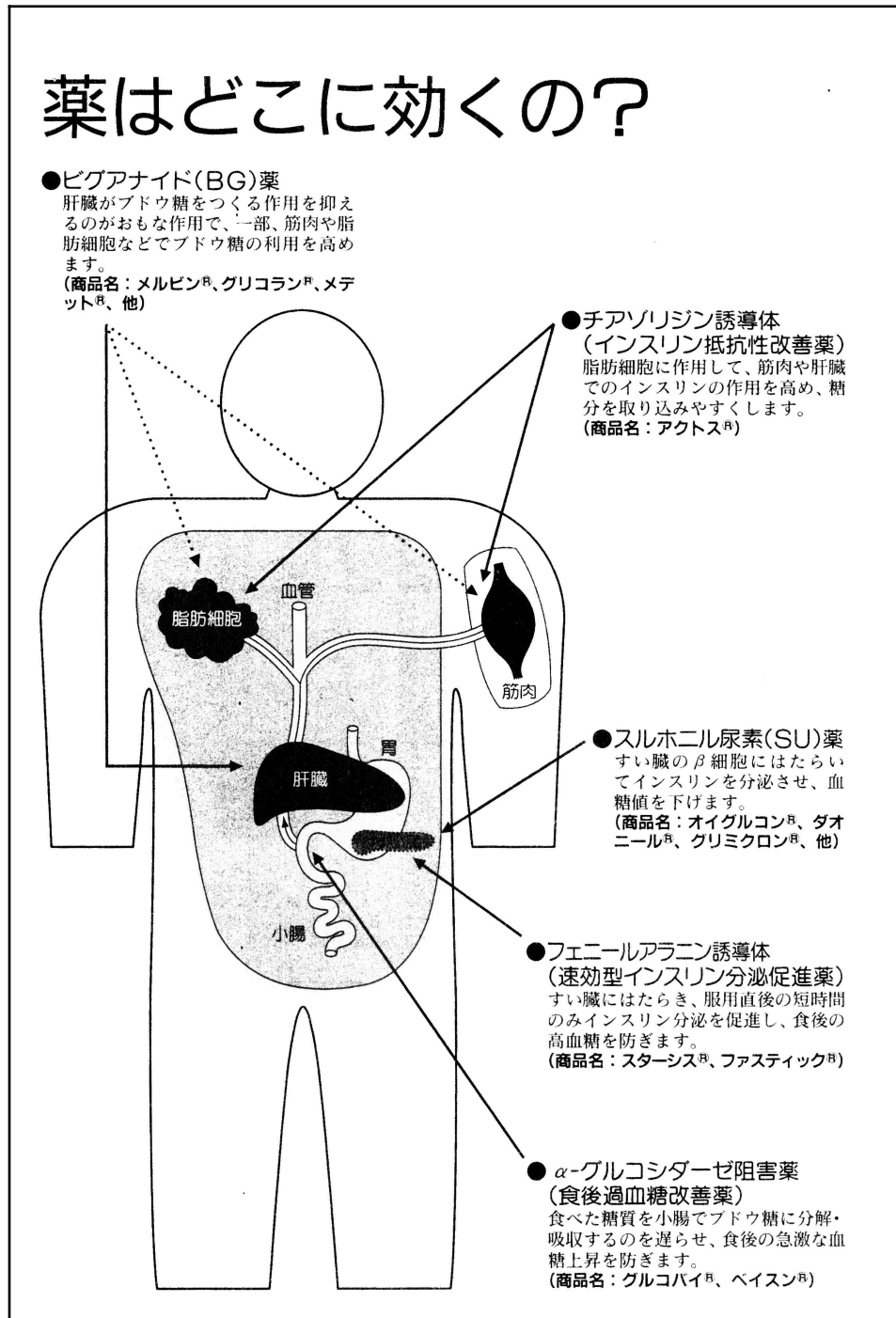


FIGURE 3-5 Putting medications on the body

Image explaining the effect of anti-diabetic medications. Source: Suzuran Center, patient education material (Courtesy of the Center)

Drugs, too, were part of the embodied practices of linking facts and values. Such interdependence of medications and lives is not—or, not only—an ethical problem. According to the *Treatment Manual for Diabetes*, it is instead a specific issue of medical practice: "The decision to start a drug therapy will not increase the efficiency of treatment, unless it is accompanied by nutritional and physical therapies. This distinguishes diabetes treatment from other chronic disorders such as hypertension or hyperlipidemia, in which medications play a central role and lifestyle changes are not indispensable. Although the improved availability and growing variety of hypoglycemic agents led to the increasing role of pharmacological agents in the treatment of diabetes, its dependence on the individual management of eating and exercising habits remains the unique feature of this disease" (Murase 2003: 219; translated by the author).<sup>96</sup> It is, in other words, the use of medication that makes its user interested and involved in her treatment.

Such invocations of self-control did not necessarily turn patients in the Suzuran Center into reluctant health enthusiasts—indeed that seemed to be the exception rather than the rule. It turned them instead into consumer-citizens who were to make the inevitable choice between therapeutic classes of medications which promised to adjust to daily routines, characters, families or individual trajectories of disease. Thus, the prescription of medicines at the outpatient clinic often followed conversations that made sure the patient was choosing not only between drugs, but between forms of life. Doctor to a middle-aged female patient: "Didn't you say you often have business meetings (*settai*) in the evenings? Will you be able to inject insulin there? or should we go on with morning shots of the long-acting type?" I can't guarantee that your blood sugar will be perfect, but it will still be better than it would be if you missed those evening shots."<sup>97</sup>

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What the concerted efforts of physicians, pharmaceutical companies and health care reformers failed to attend to is the complexity of such choices. That a person's attitudes toward his/her disease is not merely a prerequisite to drug therapy, but the very context of the metabolic processes that the drug affects. That the personal and the biological happen to be many not in a pluralist sense, but in a relational way: they are related through the choosing between various therapeutic means. As Marilyn Strathern succinctly puts it in a reflection of her recent work: "Attending to the whole person requires its own technology, its own artifacts" (Strathern 2004b: 1). And a collective of other attending persons, we may add.

Katori-san's diabetes was discovered after a motorcycle accident.<sup>98</sup> During the fourteen months long recovery his wounds healed very slowly, which led doctors to look for possible reasons until they found out that the glucose concentration in his blood was twice the normal. He was immediately prescribed oral medications, but he couldn't really keep up with the rules of life the drug required. He was a middle-aged single man living alone. "I was drinking C.C. Lemon all the time and kept working from 5 in the morning to 10 in the evening. Who had time for pills, and stuff?" Katori-san complained during an interview at his small apartment in a rainy summer afternoon. Slowly but surely, his eyes went bad, and one day he found a blister, small but unmistakable, between the second and third toes on his right foot. He went to the hospital where he was diagnosed with neuropathy, or, more simply, a kind of gangrene of the skin. "Well, I thought it's just a scratch, you know. Ain't gonna kill me, right?" But the wound became bigger and bigger, and Katori-

san had been repeating hospital stays for more than a year. He was also put on insulin to enable a better control, so he visited the nurse station twice a day to take his insulin shot together with other patients. That's where I first met him.

During these daily rites of "putting the practical knowledge of insulin injections on their bodies," patients were staring at Katori-san's gangrenous foot, while preparing the insulin kit and disinfecting the pen-shaped syringes.<sup>99</sup> When he left the room, one patient expressed his doubts about the effect on insulin, and another commented, "If he had been on insulin from the beginning instead of those fancy pills, he wouldn't have this foot now."

An old woman, finishing her own shot, turned to the nurse with a questioning look. "What type of insulin does he use? Is it good for his leg?" The nurse in charge was looking for an explanation that makes everyone in the room happy. Finally, she came up with an answer that would have probably satisfied most anthropologists, although I'm not sure about its impact on the patients themselves.

*Nurse: No, I don't think the insulin will heal Katori-san's foot. He didn't care too much until it was too late. He thought it was enough to inject insulin and that his glucose levels would go down automatically. He didn't put any effort into it. Well, he has no family, and I've heard that his job is really hard, so that makes it difficult... difficult to relate (najimu) to the medication. But, you have to know that getting well is not simply just taking insulin. You have your own share of responsibility too... so try to live up to it.<sup>100</sup>*

The nurse's answer suggests a different conception of the aim of drug therapy than what most pharmaceutical companies promise to patients, or at least what patients look for. Diabetes medications are not magic bullets, not



even insulin. People have to *relate* to them, and they, in turn, have to pass through bodies— not only vessels, but gangrenous legs too—in order to be effective. What was wrong with Katori-san, then? Although most patients in the hospital had the same metabolic disorder as he did, they kept on constructing the boundaries of silence around the domain of the pharmaceutical between themselves and the unfortunate man with his infected foot. The shooting of insulin day after day and its affect on blood sugar separated the bodies to be managed and those left to decay. Pharmaceuticals, as João Biehl expressed it very powerfully, are literally *the body that is being treated* (Biehl 2004: 486).<sup>101</sup>

## 7. Embodying differences

The detection of diabetes through blood tests and the imaging technologies that help to render the body sensitive to future disorders provide the instances of establishing disease as a normal physical condition. Disease is not something to be treated anymore, but is itself the act of treating: keeping blood sugar levels close to the normal. This kind of normalcy is neither a personal nor a biological given. It is instead a careful balancing between the two. Normal blood sugar, so doctors and nurses say, is a matter of good diet and regular exercise. Such a foreclosure of healthy life as a strategy of treatment, however, is not without its own technologies. It is a practice of disease in which human selves and pharmaceutical products are increasingly interdependent.

*Things and knowledges intersect on the body; it is this relation that IS the body.*<sup>102</sup>

Saying that scientific and human values are intertwined implies that the appropriation of medical innovations is more dynamic and conflicting than

usually assumed in social theories of medicine. As I tried to argue above, the lived body is not reduced by its encounters with particular things. Bodies and artifacts are instead part of one another.

In the diagnosis and treatment of diabetes the intermediation of technologies has also, or especially, to do with sensitive human bodies. I have attempted to point to the scientific knowledge of glucose metabolism as a multitude of texts, images, devices, and also feelings. In fact, one of the underlying arguments of actively engaging people in their own disease came from the need to make them sensitive to the invisible processes inside their bodies (Willems 1998; 2000). As in several other chronic illnesses such a level of sensitivity did not come naturally. Self-monitoring was, thus, important not only in measuring glucose levels; it was what made bodies aware of the disease in the first place. But how? CT images or blood glucose measuring devices made connectedness between sensations of pain, hunger and faintness, between visceral fat and failed kidneys, and sometimes they linked Kawaguchi-san's fast heartbeat to Murakawa-san's impaired vision.

*The more machines, the more mediation. The more mediation, the more difference. Human and non-human agency form irreducible links in the shaping of variations.*<sup>103</sup>

Mundane technologies of diabetes produced the scientific results they were designed for only on bodies that had learned to make a difference.

One reason for this may be, as existing therapies of chronic conditions in Japan show, that it is increasingly patients themselves who put these tools to use. Recent developments in microelectronics and imaging technologies, the changing landscape of welfare and health insurance during the post-bubble era, the growing concern with the macro-economic efficiency of health care delivery, a new generation of technologically literate and notoriously

independent patients, the continuing debates around OTC and generic medications and a the rapid demographic transition of an ageing population with chronic conditions have probably all played a part in the recent proliferation of biomedical innovations in Japan. Blood-pressure kits, pedometers or fat monitors were common sights in the small *eki-mae-dori* drugstores on my way home, but even less commercialized instruments of managing chronic symptoms—peak-flow meters, portable electrocardiographs—were available through most private practitioners. These mundane technologies of self-management are seen as essential in the treatment (and prevention) of asthma, allergy, hyperlipidaemia, arthritis, and heart disease, among others.

The increasing presence of such simple medical innovations in Japan calls for a shift of focus to the local settings of learning and appropriating such medical technicalities in daily life, of how people come to understand the instruments that are designed to understand themselves. As has been shown by anthropologists, putting skills to use does not necessarily *follow* their acquisition. Rather, learning is often *a part of* the very routines it brings about (Fukushima 2001; Lave and Wenger 1991). Similarly, the self-management of chronic conditions is more than simply the internalization of a technologically given knowledge. The techniques of putting mundane medical devices to use are embedded in an open-ended mediation of disease: an attunement of bodies and their affects (Martin et al. 2015; Nafus 2016).

Differences of suffering are established and drawn together in practices of pricking needles, looking at the blood flowing in one's own veins, or learning to adapt daily habits to the chemistry of drugs. At the clinic, such individual techniques provided the public proofs of biology and medicine. But it was through such proofs, indeed, that the lived reality of the body

became a site of clashing scientific and human values, something to be measured, compared and experienced at the same time.

The question that I address here, then, is not the classic polemic of medical anthropology over the scientific and/or cultural grounds of the embodied self. On the contrary, the three case studies presented in this chapter are empirical attempts to engage the critical role of particular objects and particular technologies in drawing out the connections between scientific facts and human suffering. In medical practice, rather than being opposites, numbers and suffering, technologies and meanings complement each other.

*You build up relationships like that one after another and before you know it you have meaning. The more connections, the deeper the meaning.*

The screening of visceral fat and the monitoring of blood sugar do not invade the multiplicity of bodies, neither do they generate an unlimited plurality of cultural meanings. Biological facts and individual sufferings are linked up and coordinated in these practices. It is the modes of the learning to be affected (Latour 2004; Winance 2010) and its mediations by bodies, images and tools that make all that cultural and biological differences come to matter for each other—collectively and politically—as I will pursue further in the next chapter.



## **PART II**

# **COMPARING DISEASE**



## CHAPTER FOUR

### **Trials of Difference**

*in which ethnic and gender identities are included in the clinical assessment of  
diabetes, and, later, politics is done*

*Given the increasing importance of diabetes mellitus, and especially type 2 diabetes, as a public health problem, the recognition of its myriad long-term complications, and the increasing number of potential therapies to treat the metabolic disorder(s) and the attendant complications, it should come as no surprise that clinical trials have played a major role.*

—David M. Nathan

So far, I have tried to establish that diabetes follows infrastructural routines (Chapter 2) and technological mediation (Chapter 3) that render the knowing of and suffering from disease compatible for clinicians and patients. Facts, as well as the experiences of diabetes, require immense amounts of labor at the hospital. In addition, I described how diabetes travels to the home of patients with mundane technologies, such as pills, pictures and measuring kits that literally "put" scientific values on affective bodies. In this chapter, I explore this issue from the other way around to show how such embodied knowledges are being apprehended in the science of diabetes, especially in epidemiology.

What differences should be taken into account? Which can be ignored? These questions have been increasingly taken up by researchers, regulatory agencies and drug companies in recent years as part of the sweeping rationalization strategies of medical research and innovation. The powerful administrative trends toward standardization and the homogenizing forces of



evidence-based medicine were intended to clear away the messiness of medical research in Japan too, but along the way they created new interferences between scientific and cultural claims of differentiation. This is perhaps nowhere more evident than in the burgeoning of clinical trials for diabetes. In what follows, therefore, I will argue that clinical trials are important sites for thinking about how differences come to the fore in the production of scientific knowledge.

### **1. Clinical trials: making difference**

Disease comes in many different forms, not only—as medical anthropology textbooks may suggest—in the diverse lives of diverse people, but also in biomedical science. Or, more precisely, *in between* the two. This transformation is not merely a growing concern with the ethical dimensions of treatment and the diverse needs of patients, but, as medical historian Ilana Löwy suggested long ago, a side-effect of the shift toward evidence-based medicine (EBM):

If (...) medical innovations have to make room in a 'full world,' the world is full not only with other devices and practices, but also with cultural, institutional, economic and political constraints. (...) The implementation of life-sustaining technologies [for example] interacts with cultural and religious values, as well as with instruments and tools, with the division of labor in modern hospitals, or with socialization of doctors and nurses. (Löwy 2000: 71)

The fact that in the clinic subjects and objects of medical research emerge side by side and in a constant interplay in translational medicine presents scientists and physicians with unique challenges. Peter Keating and Alberto Cambrosio have introduced the notion of 'biomedical platform' to address this movement of scientific findings move between bench and bedside and the

emerging hybrid space in which the knowledges and practices of disease have increasingly come together since the middle of the 20th century. They differentiated three levels in which these transformations had occurred: biology and medicine, science and technology and innovation and routine (Keating and Cambrosio 2003).<sup>104</sup>

Diabetes is far from being an exception. It is a disease replete with partially overlapping differences that are constantly on the move between the clinic and the laboratory. It runs in the family as a genetic predisposition in the public database of the Biobank Japan<sup>105</sup>, or threatens the nation as a lifestyle-related disease in the health care campaign of *Kenkō Nippon 21* (Health Japan 21). It is an autoimmune destruction of insulin producing cells in the pancreas when classified as type 1, or an inadequate secretion of insulin over the whole body in the case of type 2 diabetes. In yet another turn, high levels of glucose in the blood may be a daily regimen of injections for some or a choice between various pills for others.

The assessment of such incommensurable levels of disease is a constant matter of concern in the work of physicians, clinical researchers and epidemiologists. Which variations should be accounted for? How much heterogeneity can be allowed without compromising the integrity of research? What is similar and different between numbers and suffering? These are highly charged questions that require new technologies that enable the assessment of human difference and biological variation in their everyday interaction. In the process of trying to understand what different sets of numbers tell about different groups of people relations between them are being established that, in turn, articulate new forms of participation, exclusion, and inclusion.

Clinical trials are one way to do so.

Practically non-existent before WWII, controlled clinical trials became a gold-standard of evaluating the risks and benefits of medications and treatments in the current Japanese medical system. While clinical research (*rinshō kenkyū*) have been an integral part of treating diseases in hospital settings since the expansion of Western medicine throughout Japan during the first half of the 20th century, it has been due to regulatory requirements following the public scandals of drug-induced damages (*yakugai*) in the 1960s, that the category of "clinical trial" (*rinshō shiken*) was created to demarcate studies that involved human subjects. As a subcategory of the latter, studies that were designed with the aim of providing proof for the approval of new medications and medical devices came to be called "drug trials" (*chiken*). Technically speaking, therefore, clinical trials—including drug trials—are the regulatory instruments governing the conduct of scientific research in the final stage in the development of new therapies. Yet such measures of safety and effectiveness also provide the indispensable means for improving the treatment (and prevention) of diseases *through* the active involvement of its human subjects.

Diabetes is arguably one of the most clinically-studied conditions in Japan. Multi-centered long-term prospective trials that evaluate the management of glucose levels, on the one hand, have been conducted with the primary objective of *comparing* foreign findings with Japanese data raising important questions of difference and similarity. So-called large-scale prospective clinical trials (*chōki ni wataru maemuki rinshō shiken*) investigate disease mechanism by asking how a certain factor (a medication, a gene, self-management, or lifestyle) is related to the progression of complications.<sup>106</sup>

And conversely, another type of trials has surfaced the problems of generalizing the results across ethnic and racial variation. This second form

mostly includes treatment trials of new pharmaceutical innovations, or therapeutic trials (*chiken*). Anti-diabetic drug development in Japan typically involves basic research and animal experiments followed by three human trial phases: on healthy volunteers (Phase I), on a small group of patients (Phase II), and on more differentiated groups of sick people (Phase III). Patients are divided into two or more cohorts (mostly, but not necessarily, randomly) according to the therapy they are receiving and followed up for months or years comparing their blood glucose levels and complications. Given the long time-span of developing complications, the difficulty of keeping patients motivated, and the rapidly changing pharmaceutical solutions that may promise better—or easier—treatment than the one being investigated, the implementation of diabetes trials require the long-term collaboration of doctors, nurses and patients in several hospitals, and further planning and management by clinical epidemiologists, statisticians, endocrinologists and social workers.

Here, I treat the relatively recent technology of clinical trial as a provocation to rethink the everyday management of differences in the clinic and beyond as one of the central issues informing current debates over the scientific understanding of diabetes.

The notion of scientific credibility took on a life of its own in the discursive and clinical worlds of evidence-based medicine and good clinical practice. Such a quest for credibility, as I will elaborate below, is in effect an attempt to distinguish between pathological and normal conditions, efficient and inefficient therapies, safe and hazardous medications, or good and bad science. In much of the design of clinical trials, however, objects of scientific research produce and are produced through particular distinctions between human subjects, types of persons and categories of social identity. Clinical

trials are not merely instruments that channel subjective experience, cultural categories and corporate interests into biomedical research. Rather, clinical medicine is itself implicated in the invoking and fashioning of ideas of race, gender and ethnicity and their subjects. It is these generating acts of attribution linking science and persons that lead to the very politics of translational medicine, in general, and clinical trials, in particular.<sup>107</sup>

Clinical trials, as many commentators of evidence-based medicine noted, have become crucial in giving sense to the links between social inequalities and medical categories by making such links powerful tools of including patients in the production of medical facts. This innovative logic of participation has, at least in part, emerged from the complex relationship between patient organizations and the pharmaceutical industry in the aftermath of a series of public scandals of tainted blood involving AIDS patients and hemophiliacs in Japan (Shingae 2013). The tendency toward more involvement of patients in research, and a growing concern with lay experience and personal choice gave birth to a new politics of participation and accountability that came to define what may be called (after sociologist Steven Epstein) a new mode of differentialist medicine (Epstein 2007; Rabeharisoa 2008). In Epstein's powerful formulation, the *inclusion-and-difference paradigm* in clinical research is a shift of scientific interest toward social categories of identity. He addresses the simultaneous emergence of issues concerning sex and race differences in recent clinical research in the U.S. But he treats them as "analogous" and "distinct" cases, and, apart from locating "a contingent set of historical circumstances" (Epstein 2007: 232, 282), he provides little discussion of the *situations* and *events* in which such differences come to be entangled.

In this chapter, I approach this problem of differentialist medicine

through its events that mobilize new relations between different facts and identities (Stengers 2000). As I will discuss below, the medical explanation of diabetes as a loss of control underlines the critical role of ethnic and gender distinctions in the (re-)structuring of its pathology through metabolic syndrome. The risk of the Japanese population versus other Asian ethnicities is reinforced by clinical trials that prove the increasing vulnerability of men versus women. Ethnicity and gender come to stand for one another in the institutionalization of trials, which brings the scientific proof of the risk of diabetes to a full circle in the figure of the *sararīman*.

The unexpectedly generative effects of this promise of preventing disease lie at the heart of this chapter. This generativity will not, I should reveal from the outset, be found in the emergence of a blockbuster drug or a revolutionary treatment option. To date, no comprehensive cure for diabetes exist, and key participants concur that a drug is indeed among the least likely results of this collaboration to pan out. There are, however, reasons to keep reading. As we shall see shortly, the promise and threat of diabetes and its redistributive potential have sparked some curious and circuitous webs of possibility, connection, and truncation in clinical science and beyond.

There are other, and perhaps less often articulated, arguments to be made about the unintended consequences of this transformation. Jean-Paul Gaudillière has called attention to such effects in his discussion of the novel forms of science advocacy:

Of course, controlled trials are not the wonderful tool for market control and objective regulation medical reformers were dreaming of. They became instrumental in the making of specialties, the construction of markets, or the marginalization of GP's and patients' experience. A proper historical account nonetheless needs to take into account the margins for 'making things public' their existence has contributed to create. (Gaudillière 2007: 74)

Indeed, both intended and unintended effects of the transformations in the assessment of medical knowledge will be important to keep in mind as the story around the content, textures and generatives of diabetes, clinical trials, research sites unfolds, and as particular domains of cultural differentiation tack back and forth.

## **2. Recruitment: *sararīman* as a lifestyle**

Clinical epidemiological studies provide the substrate for evidence-based medicine in diabetes research by trying to establish correlations between different groups of people and the risk of diabetes or its complications in such groups.<sup>108</sup> As we have seen in the previous chapters, one area of particular concern in the treatment of diabetes is the onset of complications, which represent the major threat to patients' long-term state of health. Whether these complications are preventable has been a subject of a long-standing debate between advocates of tight regulation of glucose and those who stress the autonomy of the patient in self-management.<sup>109</sup> In the words of Dr. Tanabe, an endocrinologist at Hospital T in Tokyo, the controversy revolves around the simple question of "How much control? and in the end, it comes down to the plain choice between adjusting the drug to the patient's life, or the other way around."<sup>110</sup>

This problem has been addressed methodologically in so-called large-scale prospective clinical trials that strive to find scientifically compelling relationships between these two extremities by assessing the value of different interventions and eventually incorporate the most efficient ones into new medical protocols. Despite the controversial results of many such large-scale trials—like the Diabetes Control and Complications Trial (DCCT) in the U.S., or the Kumamoto Study in Japan—medical researchers see them as powerful

tools of filtering between effective and ineffective therapies or dangerous and innocent genes (Nathan 2002).

As Dr. Tanabe, who works in several trials, reminded me, such distinctions of evidence based medicine between good and bad science cut through other, human, differences in shaping physicians' practices: "The problem is, of course, to find the ideal participants. I have to treat patients. That's what I'm paid for. I also have to publish articles from the studies that we conduct here. And, well, you are a researcher yourself, you should know this...that I don't need just any kind of patient for good results. I have to include different kinds of groups to please ethical boards and editors' strict requirements on inclusion criteria. This is rather difficult, because in studies that are funded from Japan, you have to say something about the particularity of the Japanese data, but then statisticians insist that we include different [social] groups, or, say, pregnant women. And if you say that, see, these are my the patients, I have to treat them, I don't *choose* them! Then you're told, well, 'how can we produce some feasible data from such a boring sample?'"<sup>11</sup>

Let's put it like this: the scientific problem of *what* diabetes is happens to be very strongly related to the problem of *who* should be treated. Although "not just any kind of patient" is a good patient in a scientific sense, clinical studies have to start from a simple premise of disease: that it is located in hospitals (after all, that's what makes clinical studies *clinical*). When people feel sick, they go and see a doctor. So much, at least should be taken for granted. Some people, however, don't consider their condition that bothersome at all, or just never have the time to go and get a checkup. Others, in contrast, may go even if they don't feel anything at all, because they are at risk. Or, so they are told.



The first and one of the most critical tasks researchers of diabetes in Japan have to confront is the chronic shortage of patients willing to participate in trials. This problem is particularly overwhelming in epidemiological studies, which lack even that slight prospect of a new and better medication offered by pharmaceutical trials.<sup>112</sup> I observed several long conversations in the office of the clinical trial coordinator at Suzuran Hospital, where the latter tried to persuade patients about the benefits of being closely controlled by a clinical staff and "leading experts" of the field. Normally, the coordinator would stake claims to science seeking to invoke a sense of trust in the sick person while earnestly specifying a long list of possible risks involved: "Would you please carefully read this consent form before you put your seal on it?"

Questions of access and recruitment are decisive not only in terms of who will be enrolled in a trial, but also in terms of what will be studied. Scientific articles have much to say about alternative methods for finding appropriate individuals to participate, about who is being included and excluded (and how) in the process of making facts. Facts, for example, that prove the efficiency of lifestyle modification in the prevention of type 2 diabetes:

Male subjects with IGT [impaired glucose tolerance; added by the author] recruited from *health-screening examinees* were randomly assigned in a 4:1 ratio to a standard intervention group (control group) and intensive intervention group (intervention group). (...) *Only men were selected* for the present study, because in our previous long-term follow-up experience there were more dropouts among the women than among the men in a similar setting. (Kosaka et al. 2005: 152–153)

That epidemiological studies make use of health-screening as an entry point to trials makes some sense, given that the most likely way for people with, or at risk of, diabetes to encounter the medical system is through the annual physical checkup. Men may be too busy to start eating proper breakfasts and go down to the gym in the evening, but they are ideal research subjects. They are less likely to quit trials once their health-check results prove them to be at risk, not least because next year they have to repeat the checkup either way. Thus, being a working man (rather than a working woman, or a self-employed man) may come as a scientific parameter, an *inclusion criteria* in some cases.

But the fact that masculinity is a salient aspect of treating and diagnosing diabetes from the very admission of patients is a detail left unaccounted in most studies. The diabetes clinic, thus, offers a point of departure for discussing how the process of recruitment enters another administrative practice, that of hospital admission.

In Suzuran Hospital in the then-current service a great majority of people have been referred to the diabetes center by private practitioners, public health departments and companies as a direct consequence of their yearly preventive health checkup results. While fasting glucose levels that these results indicate are numerical values derived from a single blood sample, it comes as part of a more composite system: the annual health checkup (*kenkō shindan*).

Although voluntary health screening is widespread in Japan, mandatory check-up, at the time of my research, was restricted to people above forty years of age working full-time in enterprises with more than fifty employees.<sup>113</sup> As things go in Japan, many women quit their job during pregnancy and most of them return later as part-time workers. So, men are

screened more often than women not by any virtue, but as a consequence of the organizational infrastructure of the annual health checkup, which situates the male corporate employee, or *sararīman*, as the primary subject of diabetes and its clinical research. The confluence of the subjects and objects of medical research, thus, emerge from the everyday operations of the medical checkup.

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The logic of screening is the reverse of that underlying population surveys in which demographic cohorts depend on the individual differences taken into account. Here, on the contrary, it is the criteria of the individual's risk of diabetes that comes to be evaluated on the premises of a "population." Epidemiological data that indicate a growing rate of diabetic complications with age, for example, may serve as a rationale for measuring waistlines and blood sugar levels in people above forty. But they indicate different problems for men and women, as Dr Nazono, the senior physician at Suzuran explained to me in an interview. "We thought before that glucose levels didn't show significant differences between the sexes, but we were quite wrong. It is clear from survey results now that men are most vulnerable in their 50s and 60s, while the number of female patients keep rising linearly with age. But, believe me, this is not simply an epidemiological problem. I'm talking about individual cases. I see all these relatively young working men day after day and, yes, I know that they have absolutely no time and energy for eating healthy food or jogging in the park. They're just too busy, which makes it very difficult for me to help them. So, the complications strike down on them much faster than on women who pay more attention to their health and will develop the disease later in their lives."<sup>114</sup>

During the prosperous years of economic growth between the 1960s and 1990s, the *sararīman* (literally, wage-earner; or corporate employee, in a narrower sense) represented the new lifestyle of the young, urban middle-class. Arguably, it is exactly this age-cohort that later suffered from chronic conditions, called 'lifestyle-related diseases' (*seikatsu shūkan byō*) during the long years of recession since the mid-1990s.<sup>115</sup> While being a *sararīman* paved the way to health screening and clinical research, at the clinic, it presupposed some idea of unhealthy lifestyles and the difference between men and women (Figure 4-1). Sex categories, which in the quoted population survey<sup>116</sup> pointed to the different biological courses of disease (developing later in women than in men), turned diabetes at the clinic into a gendered phenomenon of the busy *sararīman* and the healthy housewife who lives longer.<sup>117</sup> Men's well-defined daily routines of smoking, drinking and no exercise made them relatively easy subjects of compartmentalized health advice on lifestyle changes.



**FIGURE 4-1** Men, women, Japan, Europe (Diabetes textbook)

Popular health textbook of diabetes explaining that in Japan it is men who are more at risk contrary to Europe, where women are more vulnerable. (Source: Tokyo Metropolitan Institute of Gerontology 1993: 13)

A further constitutive instance of diabetes as a men's health issue at Suzuran was the afternoon outpatient counseling for patients with erectile dysfunction (quite tellingly, however, it was the English abbreviation in use all over the clinic rather than the Japanese word for impotence). This program was launched and supervised by the director who had been a vocal advocate of the need for reaching out diabetics with down-to-earth messages. The establishment of the consultation program was part of his personal involvement in the exploding research into the relationship between sexual dysfunction and endocrine diseases, as well as a strategic opportunity to engage men in the treatment of diabetes. While he was slowly building up a reputation as a highly indulgent physician, his male clientele gradually grew and the consultation became quite a success.

One afternoon when I was in the exam room where Dr. Mihara was talking to a seemingly embarrassed middle-age man about his "ED problem". He mentioned studies that showed the correlation between impotence and diabetic neuropathy (nerve damage) and underlined over and over again the possibility that the man's problem may have been diabetes itself rather than his waning male virility. "Look," he said, "you can keep experimenting with all kinds of fishy drugs on the internet (...) But I would instead recommend you to get to the source of the problem, which is the control of your glucose level." Stressing the damage of the nerves that happens to the penis might not be the most elegant mode of patient education, but that is less my concern here. The reason for quoting this episode is rather to show how physiological differences between men and women perform masculinity in the clinical work of diagnosing diabetes and linking up patients with clinical research.

The marked category of the *sararīman*<sup>118</sup> at the clinic elicits a number of important issues regarding the distribution of biomedical knowledge across

cultural differences in diabetes research. One is the concept of lifestyle. Indeed, diabetes has been understood both in Japan and elsewhere as a lifestyle-related disease, which means one's everyday routine has to be taken into consideration from the beginning of the treatment. It requires complex cultural assessments from eating habits to daily walking distances. But how can so diverse aspects be included in clinical studies? How can they be compared? The figure of the *sararīman* helps to turn such multiplicity into a fact of 'lifestyle'.

### **3. Lived facts of blood sugar**

The notion that (harmful) lifestyle is the cause of and the key to controlling type 2 diabetes is the guiding assumption behind epidemiological research that call for better public health strategies and multi-billion-yen drug development programs, which promise chemical solutions to "bad" habits. It is, consequently, the condition of possibility for any scientific knowledge about diabetes.

It was certainly so for the researchers in Suzuran Center who participated in setting up the Japan Diabetes Clinical Data Management Study (JDDM), a multi-center research that was expected to produce evidence on the effects of active intervention in the prevention of complications. The largest study of its kind, it brought together close to seventy clinics around the country that collaborated in the observational study of more than 60.000 patients. Funded by the Japanese Diabetes Society, the JDDM has been collecting laboratory data of diabetes indicators, such as HbA1c and analyzed it in the light of complications developed by patients. Doing so, they were slowly but surely piecing together all epidemiologists' dream of a comprehensive national registry of diabetes therapy. Meanwhile, the original

research, which started in 2000 as a study group of specialists, evolved into as many as eleven independent projects by 2007 thanks to a computerized system (CoDic) provided by the leading insulin manufacturer, Novo Nordisk, and the collaborative work of statisticians, clinicians and public health experts.

While these independent studies were still going on, the first preliminary results were published during 2005 in the middle of the so-called metabolic syndrome controversy (see below). The authors were stressing the "superiority of Japanese HbA1c levels" when compared to other, especially Asian, countries. They also suggested that complications could be prevented by patients' education on lifestyle and additional diabetes treatment; and that the intensive intervention based on monthly visits in Japan could serve as a lesson to other countries.

The reason I cite this research is to demonstrate how lifestyle becomes a momentum for mobilizing collective attributions, such as "Western" or "Asian" attitudes in managing diabetes. To be sure, not by rendering them to the realm of the social, but rather by measuring it accurately in changing hemoglobin levels:

In UKPDS [UK Prospective Diabetes Study], the average HbA1c was 8.0% in conventional treatment group and in Asian countries, the average HbA1c was 8.5% in type 2 diabetes. Our results are unlikely to be due to selection bias since the medical institutes in this study are evenly distributed throughout Japan on both a geographic and socioeconomic basis. The accuracy of most of the institutes and laboratories conducting HbA1c measurements was confirmed with standardized samples supplied by the JDS [Japanese Diabetes Society]. Therefore, the results are unlikely to be due to selection biases or measurement errors. (Kobayashi et al. 2006: 202)

When 'lifestyle' is expressed as HbA1c levels, it becomes a transportable fact. It can move across oceans either as a medical parameter or a cultural stereotype, although not always neatly tied together. A patient, participating in the above study, echoed this mobility when she recounted her visit to the U.S. To her greatest surprise, one of her relatives was encouraged by his physician to cut back on bread or pasta in his daily menu, if quitting ice cream had been clearly improbable. "They just simply calculated daily calories, I guess," she commented and told me how she had tried to explain him that rather than daily measures, he should find out about his HbA1c levels at the hospital, because they show his condition more fully. "I told him to check his hemoglobin results to see the effect of such advice, but he didn't listen. He said he was feeling fine, so why to worry so much. No wonder, so many Americans end up with their legs cut off," she concluded.<sup>119</sup>

#### **4. The metabolic syndrome controversy**

Ethnic difference is a persistent theme in diabetes research from the bureaucratic jargon of grant proposals to the lurid tabloid headlines of scientific findings reporting about "The Asian Epidemic," or raising questions like "Are Japanese people prone to diabetes?" Clinical trials are by no means exceptions; on the contrary, focusing on the ethno-racial variations of disease is a key strategy of clinical epidemiological studies. At the time of my fieldwork in Japan this question turned into an issue of intense political and scientific dispute, the so-called Metabolic Syndrome Controversy (*metabogiron*).

When the three amendments to Japan's Health Insurance Act were passed by the Diet on June 14, 2006 as part of the ongoing health-care system reforms,<sup>120</sup> it was mainly the latter two about the partial reduction of medical



benefits for the elderly that seized the attention of the media. The third reform bill seemed to be less politically charged. But only at first glance.

According to this revision health insurers would be required to provide annual health checkups to all Japanese citizens between 40 and 74 years of age and further advice to those at risk of 'metabolic syndrome,' a group of conditions linked to diabetes. The stated goal was to control health care costs by a 25% reduction of the number of metabolic syndrome cases between 2008 and 2015.

The term 'metabolic syndrome' has come to assume an increasingly central position in Japanese discourses on public health issues as a new technology for producing evidence about the cardiovascular risks of diabetes (see *Appendix 4-1; 4-2.*). But the implications of the revision of law and related findings published in Japanese and international scientific journals remain unclear (Landecker 2011; Lipphardt and Niewöhner 2007; Nango and Saio 2006; Yamanaka and Furukawa 2016).

Part of the problem lies in the effort to determine the relationship between risks and pathologies. The diagnostic criteria of metabolic syndrome are based on numbers: amounts of fat around the waist, blood pressure and blood sugar. Such numbers indicate disease. Not now, but in the future. And not equally for everyone. To complicate matters, clinical research on the complications of metabolic syndrome and diabetes is routinely conducted in ethnic/racial and gender groups. Relations, again, have to be established to account for such variations.

The Japanese Society of Internal Medicine with eight further organizations compiled the diagnostic criteria for metabolic syndrome in April 2005. The pillar of this definition became the waistline: more than 85cm and 90cm for men and women respectively were judged to be the threshold

values for the syndrome (Examination Committee 2002). So, when visceral fat was chosen to be counted, women tended to be less vulnerable to metabolic syndrome than men—given that they were Japanese, because in any other countries the numbers for men would be higher. The tension between ethnic and gender differences surfaced along with the numbers. And once in the middle of debate they generated even more differences.



**FIGURE 4-2** Cut-off points for the risk of metabolic syndrome

Cut-off points set by the International Diabetes Federation for the risk of metabolic syndrome in men and women. Source: *Asahi Shimbun*, June 17, 2007., Morning Edition, p.1.

The International Diabetes Federation, a transnational association of diabetes experts, after first accepting these results, later decided to revise the Japanese values conforming them "with the rest of Asia" (International Diabetes Federation 2006). Whether the Japanese are Asians or not, and if so, how much they are, cut to the core of anthropological interest (Nomura 2012; Umesao 1998; Yamashita 2006). But endocrinologists put the emphasis elsewhere. Matsuzawa Yūji, the leader of the Japanese committee, cited CT scans and magnetic resonance imaging (MRI) to underline the credibility of the Japanese data versus other Asian countries where research has been conducted, or so he supposed, with less methodical arrangements. Critiques,

on the other hand, pointed out the under-representation of women in the Japanese sample. The controversy was unfolding around the design of the study, between technologies of screening and the methods of inclusion (*Figure 4-2*).

It was now politics' turn. The metabolic syndrome controversy exploded before a Diet committee in May 2006, where Kōri Kazuko, an opposition representative—one of the few female members of the Lower House—attacked the proposed reform bill. She hit the very nerve of the revision by questioning the scientific credibility of 'metabolic syndrome':

The case of metabolic syndrome highlights the abuse of the word 'evidence' (*ebidensu*). 'Evidence, evidence, evidence,' they keep saying to things which aren't evidence of anything, only to justify the reduction of the state's health care costs and shift its burden on the citizens. And you call that a reform bill! (Source: MHLW 2006; translated by the author)<sup>121</sup>

She cited the joint statement of the American Diabetes Association (ADA) and the European Association for the Study of Diabetes (EASD) about the inaccuracy of the diagnostic criteria of metabolic syndrome and pointed to the interlocking of public health with the pharmaceutical industry. Later, in an interview for *The Japan Times*, she accused Matsuzawa of a conflict of interest in the course that led to the definition of 'metabolic syndrome' referring to his participation in a meeting sponsored by a drug company (Otake 2006).

What began as a debate over medical thresholds ended up being about much more.

Thanks to technological sophistication on the one hand and political work on the other, the word 'metabolic syndrome' was transforming itself into a site of what Evelyn Fox Keller has, in a different context, called "productive uncertainty" (Keller 2002). Significantly for the diagnosis and treatment of

diabetes in Japan, the controversies surrounding the definition of metabolic syndrome generated conceptual issues and political tensions in a deeply reciprocal fashion.

## **5. The Japan Diabetes Complications Study**

The emphasis on the under-representation of Japanese people in the international epidemiological literature is a recurring theme in publicly funded studies. On the other side of the coin, just as well, reporting on the discrepancies of the Japanese data as compared to other results may facilitate the entry to scientific journals and conferences which have been increasingly committed to diversity versus universalism in the past two decades. Thus, many studies indicate the importance of a locally generated knowledge for the etiological understanding of diabetes in their objectives and aims section.

Consider, for example, the so-called Japan Diabetes Complications Study (JDCS), the largest and longest trial focusing on the effect of lifestyle modification in type 2 diabetes. It was conducted in 59 clinics nationwide including 2,205 patients randomly assigned to a conventional and an interventional group. The latter received telephone counseling, personal diaries to record daily habits and laboratory results, and pedometers to count walking steps, among others. Where lifestyle is concerned, a great deal of its intervention comes in the form of mundane techniques and strange objects that adjust the treatment to individual patients who have to learn to use them before the researchers' long-awaited differences begin to surface.

But so too is much of the concern with lifestyle a contested domain of national identities that may be brought out from the hotbeds of science. In 2002, the WHO's recommendation for a single Asian threshold of obesity framed a heated debate on the pages of *Lancet*, the leading British medical

journal, about the ethnic variations in Body Mass Index (BMI).<sup>122</sup> As two of the JDCS researchers wrote in the correspondence section, the lack of comparative research between ethnic groups in general made any conclusive statements close to impossible. Next, not without a certain degree of immodesty, they cited the data from the British UKPDS trial and their own findings as the single comparable scientific data on this subject concluding that the only significant difference of the two groups was in their BMI:

Comparison of data from two prospective studies reveals a striking difference in the average BMI of type 2 diabetic patients from two different ethnic populations—white individuals from the UK Prospective Diabetes Study (UK Prospective Diabetes Study (UKPDS) Group) and Japanese patients from the Japan Diabetes Complication Study (JDCS). (...) The origin of this large difference in BMI is unknown, but it might reflect differences in insulin secretion and sensitivity between the two ethnic groups. (Sone et al. 2003: 85)

The study evaluated these two kinds of intervention with the explicit aim of assessing and interpreting the differences in responses to them along with the ethnic variation in vulnerability to diabetes. The small but statistically significant differences in BMI values between the two therapeutic groups targeted by the JDCS emerged alongside other, not less significant, but probably more controversial trajectories of national epidemiologies: sensitivity and obesity became the focal points of difference.

In referring to the scientific debates of delineating ethnic-specific characteristics, it is hard not to notice how such theoretical issues are not simply shaped (or constructed) by, but are actively processed through the technological toolkit of the clinical trial. As stated in its annual report, JDCS researchers were keeping one eye on widely accepted prospective studies of diabetic complications, such as the American DCCT for type 1 or the British

UKPDS for type 2 diabetes when they designed their own research protocols. These trials, as the Japanese physicians themselves admitted, have set new standards for clinical research during the 1990s by providing important proofs of tight regulation in the intervention of diabetes.

## **6. Inclusions: the new publics of diabetes**

The disputes around the absorption of epidemiological proof from clinical research in Japan and elsewhere brings out an elaborate narrative about the *inclusion* of cultural difference in the assessment of biological variation I tried to bring light in this chapter.

Historians and philosophers of science have thoroughly documented the powerful influence of public scientific experiments and how they have mediated between human affairs and the production and management of things in Europe since the 17th century (Haraway 1997; Shapin and Schaffer 1985; Stengers 2000). Anthropologists and sociologists, on the other hand, added important new insights to this line of research by exploring the ways experimentation creates its own worlds, collectives, and divisions (Callon and Rabearisoa 2008; Epstein 1996; Fortun 2001). Those authors who highlight the inclusion of lay people and values in the conduct of scientific research often regard this as a new regime of knowledge production that goes *beyond* the laboratory.

The way diabetes has become a matter of epidemiological concern in Japan during the past decade foregrounded diverse modes of collective identities: why are (working) men more at risk? how are Japanese more vulnerable than other Asian populations? Such "creative qualities of interconnection across difference," which Anna Tsing calls 'frictions' (Tsing 2005), are crucial in understanding the public engagement with science and

technology in medical care. There are, indeed, fundamental tensions between metabolism as physiological variation and metabolism as political confrontation, metabolism as ethnic and gender identity and metabolism as a scientific problem. And yet, such tensions also imply a confluence between biological and cultural distinctions both of which become evident in the process of dealing with disease.

First, there are questions at the level of clinical medicine about *different facts* and how they should be weighted: how do waist sizes, blood pressures and glucose levels relate to each other? Is this a statistical matter? Or, rather, a medical problem? Where are the answers to these questions located? Is it the person under treatment? His/her body? Or the Japanese nation? Or a universal human? And yet, how are these different scales properly translated into each other?

This leads to a second kind of *difference*: that of *gender*. For men's and women's bodies are different but not in a straightforward way. It depends on the criteria one chooses to evaluate, say, metabolic syndrome. Who is supposed to decide such criteria when competing statistical, medical and political experts disagree? How will such conflicting paradigms come to account for a single disease entity? In the case of the cardiovascular risk of diabetes such controversies point to a third level of difference between Japanese, Asian and Western values. Are men and women differently different in Japan than elsewhere? If so, are they different genetically? Or culturally? Or both?

The publics of diabetes have become part of the knowledge about disease through technologies like clinical trials and annual health checkups that articulate new biopolitical modes of ordering and knowing the world. A world in which men are more at risk of diabetes than women *because* they are

Japanese men. Realities of ethnicity and gender become apparent when they are included as scientific facts. Clinical trials are, of course, only one among the numerous technological modes that enable such inclusion of ethnic and gender identities (and it's probably fair to say that it is not even among the most important ones). If so, then it should be clear that such identities are neither given, nor constructed, but rather practiced and multiple. Questioning inclusions is, therefore, a way of exploring the nature of how (bio)politics is *done*.

The enduring controversy over the metabolic syndrome brings us to the question that the present and the next chapter revolve around: *how do such differences interfere with each other?*





## CHAPTER FIVE

### Assembling Variations

*in which genetic variations interfere with the variations of population, but drugs may help*

The social perception of the distinction between "working men" and "housewives" and the physiological differences between Asian and Japanese bodies, as I have stressed, *include* one another in the daily practices of clinical science. The body of the diabetic patient—from blood vessels to kidneys, from (thrifty) genes to fat bellies—is among the most important sites of technosocial innovation that facilitate relations between individual and collective identities. It is here where the *sararīman* meets other "sararīmen" in his search for a treatment, and it is here too that lifestyle and pathologies encounter each other in the epidemiological comparisons of living with elevated sugar levels in the blood. And while epidemiological comparisons are global enterprises, their achievements are situated in local—or, rather, 'localist'—concerns. With Bruno Latour, "scale is the actor's own achievement" (Latour 2005a: 185; cited in Blok 2013: 188).

Take, for example, the findings of the JDCS study, mentioned at the end of the previous chapter: "There had been some doubt for a long time as to whether the kinds of evidence gained from studies conducted on Western subjects are applicable in Japan as objectives of medical intervention and health care policy given the significant differences in genetic and lifestyle factors of Japanese diabetics" (Yamada et al. 2004: 3; translated by the author). Note that here it is genes along lifestyles that frame differentiation: genes (there are many!) that make Japanese people more susceptible to diabetes

than others, and Western lifestyles that seem to make things even worse. Hence, the networks of "global" epidemiology are folded into "local" concerns with the risk of diabetes.

In one of the most influential passages of her now classic work *Encounters with Aging*—known simply as *Kōnenki* (Menopause) for Japanese readers—Margaret Lock argued against the implicit separation of the "biological" from the "cultural" in studies of medical anthropology:

(...) not only that cultural beliefs influence the construction, experience and interpretation of aging and other biological processes but that biological difference—sometimes obvious, at other times very subtle—molds and *contains* the subjective experience of individuals and the creation of cultural interpretation. A dialectic of this kind between culture and biology implies that we must contextualize interpretations about the body not only as products of local histories, knowledge and politics but also as local biologies. (Lock 1993: 39)

The present chapter is an attempt to bring this notion of "local biologies"<sup>123</sup> to bear on thinking about molecular, environmental and ethnic variables as they interfere in the quest for producing credible scientific evidence of the genetic risk of diabetes.

Contrary to classic "genetic diseases," like sickle-cell anemia or Huntington's disease that are supposedly caused by a single mutation in the structure of DNA, in diabetes genetic information does not easily translate into cultural categories of race or personhood. This doesn't mean of course that diabetes research has not been influenced heavily by the emergence of the "new genetics" during the past two decades<sup>124</sup>, but along with other complex diseases, such as Alzheimer's or various forms of cancer, possible genetic factors do not provide definitive tools for diagnosing future susceptibilities.<sup>125</sup>

Until recently, such susceptibilities were a concern for epidemiologists rather than molecular biologists, and most forms of diabetes have been framed as lifestyle-related or autoimmune conditions in the popular imagination in Japan. But, although genetic work is likely to be done in laboratories with mice and microscopes, while epidemiologists study human populations on statistical tables, the objects of these two kinds of research *interfere* in the case of diabetology: rather than one determining the other, new and original differences emerge.

The following story of genomic research will allow me to explore further how these two trajectories of differentiation come to stand for each other in the collaborative arrangements between laboratory, clinical and regulatory activities.

## **1. From differences to assemblages**

Over the past three decades, massive innovation in biotechnology and the life sciences in general turned many intimate medical matters into moral concerns, generating new forms of relatedness between sciences and their publics. In a variety of ways, this has been commented upon and explored in anthropology and science studies, from the emergence of new biosocial identities to the novel configurations of scientific research. One may indeed argue that genetics—along and in connection with information technologies—has undermined many of the epistemological foundations of these two fields, namely, the concept of kinship in anthropology (Franklin and McKinnon 2001) and the paradigmatic status of physics in many STS models that used to describe the relation between science and society (Haraway 1997; Rheinberger 2010).

Some social scientists celebrate these changes as a genomic revolution,

while others refer to it as part of a new eugenics of race. And while there has been an elevated interest in the weighty political and societal issues that accompany the "new genetics" in different countries, most of these technosocial changes are examined as if they were local variations of a global transformation, including transnational science, the pharmaceutical industry, and supposedly universal moral dilemmas, such as race or health.<sup>126</sup> Importantly, from the point of view of the present chapter, such minute descriptions of ethical controversies over genetic diagnosis or the impact of patient movements on medical science are supposed to carry the potential to compare various alternatives of decision making and regulatory strategies in general.<sup>127</sup>

Such a comparative framework is even more present in sociological and historical inquiries whose geographic focus is East Asia. As Wenmay Rei and Terence Hua Tai wrote in their introduction to the EASTS special issue "Biotechnology in East Asian Societies: Controversies and Governance," "through *different* focuses in the context of *different* societies, [we] aim to shed light on the nature and dynamic of scientific governance for biotechnology in East Asian societies" (2010: 5; emphasis added). What is suggested, in effect, is that scientific and social facts come to stand for each other in their political manifestations. So, describing *different* biotechnologies through social controversies and regulatory activities locates the comparative potentials of genomics by keeping differences and similarities (of genes, ethnicities, markets, etc.) oscillating among political, methodological, and ethical frames of reference. To bring out this potential, however, we might explore such differences further within scientific practices to see how multiplicity is integral to and articulated by the methods and practices of biomedical research.

In recent years, such "ontologies of difference" have become the focus of an emerging literature at the intersection of anthropology and STS that endeavors to treat theoretical concerns as ethnographic facts and vice versa by asking in what ways and for whom differences and similarities come to matter in scientific practices (e.g. Choy 2011; van der Veer 2016).

One way to get away from the idea that differences come in distinct packages—of culture, science, the self, or what have you—Marilyn Strathern has recommended that we engage in a postplural approach (2004a: xvi).<sup>128</sup> In contrast to pluralist modes of analysis that assume the incommensurability of mutually exclusive perspectives, in a postplural world, domains are always partially connected through their differences and the work of comparison. Drawing on years of ethnographic fieldwork in Papua New Guinea, Strathern has developed a theoretical apparatus that incorporates and mobilizes the differences between Euro-American and Melanesian worlds as a hybrid mode of understanding both. Common objects of identity formation that seem to belong to single logical orders—for instance, sacred flutes used by the people of Mount Hagen or various reproductive technologies in the Western world—emerge here as tools of a novel kind of comparative research: the exploration of the relations between divergent concepts, such as kinship, gender, or modes of exchange (Strathern 1988). Her insistence upon treating comparison as both a conceptual tool and an empirical interest provides a virtually inexhaustible resource for the "crossbreeding" between STS and anthropology.

It is this often-neglected aspect of comparative practices working between difference and sameness, as well as theory and practice, at the same time that I address in this chapter. The following story of genomic research allows me to explore how epidemiological and genetic trajectories of differentiation come to stand for each other in the comparative encounters

across laboratory, clinical, and regulatory activities. Here my aim is to bridge the methodological prospects of the postplural approach and recent anthropological inquiries into the Deleuzian notion of the assemblage (Jensen and Rödje 2010; Ong and Collier 2005; Rabinow 2003). Rather than asserting a static—social, biological, and so on—commensurability among genes, populations, and markets, these three planes of research came to constitute the ethnographic focus of this chapter through a series of comparisons across molecular biology, epidemiology, and drug discovery. Such comparisons are not after-the-fact anthropological interpretations but a collaborative conceptual work through ethnography and medical science propelled by the emergence of adiponectin and the multiple connections between human and nonhuman entities that it made possible. Finally, the chapter argues that exploring the emerging assemblages in and around biomedicine may be one way to put anthropology in motion in order to overcome the static notions of comparison and pluralism so deeply inscribed in ethnographic research strategies.

## **2. "Our thrifty genes"**

In September 2001, physicians and geneticists from all over Japan convened in a large lecture hall of the famous Prince Hotel in Sapporo to discuss the future of genome research and its applications in the fields of medicine.<sup>129</sup> Since it occurred half a year after the official release of the first draft of the human genome sequence, it is probably no surprise that participants of the symposium were hotly debating the hows and whats of the next, postgenomic, phase of genetic research (Sunder Rajan 2006: 199–200). Most of the researchers in the hall seemed to be convinced that the emerging work on

gene function and expression would require new forms of collaboration among physicians, biologists, and pharmacologists if Japan wished to maintain its position in the increasingly competitive transnational environment of medical research and pharmaceutical business. But there was less agreement as to exactly how.

In a talk titled "Genetic Basis and Molecular Mechanism of Type 2 Diabetes in Japanese People and Its Personalized Treatment,"<sup>130</sup> Dr. Kasahara Toshio, a leading diabetologist from Tokyo, was speculating on future strategies of what he called the "order-made treatment" (*ōdā meido chiryō*) of diabetes. He was a pragmatic man, as I learned later on, but at this first encounter, more than anything, he made the impression of a visionary. He took his audience through a breathtaking scientific journey that stretched from hunter-gatherer ancestors somewhere in continental Asia to twenty-first-century genotype-diagnostics-based drug prescriptions in Japan. Significantly, it was a gene or, more precisely, a hypothetical gene<sup>131</sup> that mediated among such scales of time, space, and human behavior.

The notion that diabetes might be caused by some unknown genetic material had been put forward by the American geneticist James Neel in the early 1960s and entered into the epidemiological imagery as the thrifty-genotype hypothesis long before the recent genetic hype (Neel 1962). With the increasingly complex understanding of the hereditary mechanism of diabetes during the 1980s, however, it lost some of its luster, culminating in the author's own rejection of his theory (Neel 1982). It was a slightly outdated model, then, that Dr. Kasahara recalled in his presentation, an idea that every diabetologist knows by heart (*Figure 5-1*).



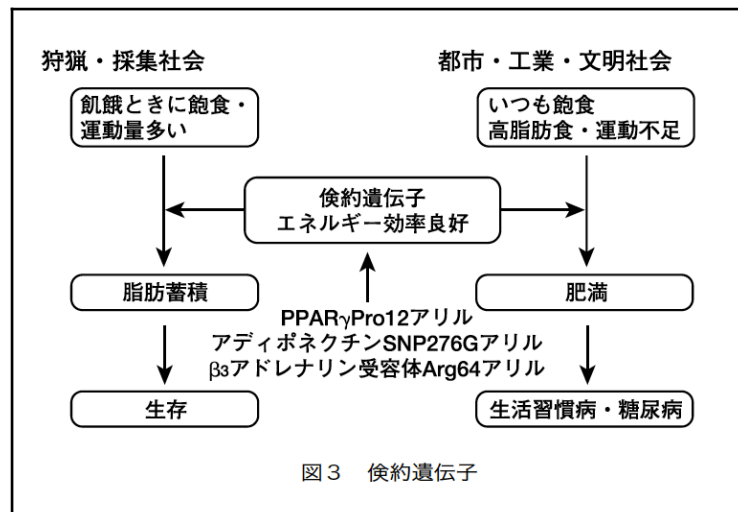


FIGURE 5-1 The thrifty genes hypothesis

In the thrifty gene (or its hypothesis) two different forms of simplifications of eating habits and genetic pathways added up creating a new form of complexity. (Source: Kadowaki 2003: 48).

The story goes as follows. For ancient hunter-gatherer societies, the quick conversion of sugar into fat had been a metabolic advantage in times of food shortage. Those who survived these not-so-rare famines, therefore, may have developed a genetic makeup of resisting the work of insulin that would instead help that sugar to turn into energy. Consequently, those populations that still carry this imaginary thrifty gene (or genes) become more prone to diabetes when their daily life no longer requires the storage of calories but their bodies keep accumulating the fat. What had been a state-of-the-art symposium on genomic futures suddenly evolved into a comparative history of Japanese genes and Western lifestyles whose value and position were mediated by this holy grail of diabetes research: the thrifty gene.<sup>132</sup>

In a sharp turn, however, Dr. Kasahara went on to project no less than the finding of a possible thrifty-gene candidate in the not-so-distant future, elaborating on the preliminary results of his team in Tokyo that was targeting

the molecular mechanism of adiponectin, a newly discovered fat cell hormone. He ended his lecture by hinting that the meticulous nature of such research could not be victorious without combined incentives from industry and public health policy, and he held out the carrot (in the form of a gene) of a diverse market of drugs, on the one hand, and an ethnic notion of disease prevention, on the other.

Next, a senior university professor stood up and asked the speaker how eating habits matched up to genetic traits in the exhibition of the differences between the insulin resistance of European and Asian populations.

*Dr. Tsubaki: I myself used to think about this in terms of thrifty genes (kenyaku idenshi) too, but, on second thought, it seems obvious that agriculture is a better way of accumulating food than hunting and gathering. If what I'm saying is right, the difference of insulin secretion [between Caucasian and Asian populations] lies [not so much in genetic predisposition, but] in eating habits.*

*Dr. Kasahara: Yes, you're absolutely right. I think the differences in insulin secretion reflect different eating habits. But here you are talking in terms of thousands of years. Yet, on the other hand, if we go back as far as 200,000 years to the birth of humankind, [we know that] there was some kind of an ice age that brought the human race to the brink of extinction [sic]. So it's possible, I think, that in this age some people, who were able to store small amounts of food as fat, somehow possessed an energy-efficient thrifty gene, which helped them [and their offspring] to survive.*

The ethnic variability of insulin secretion and resistance implies differences, but what kind of differences? That of thrifty genes? Or, rather, eating habits? For Dr. Tsubaki, the former explanation was leading *away* from the latter. For Dr. Kasahara, on the contrary, the latter was only explicable in

the light of the former. He enacted dietary differences through the difference in genetic vulnerability, where the two variations figured in each other: the historical traits of the thrifty gene grounded lifestyles in genotypes and gave genetic differences their scientific credibility by linking them to the culturally relevant categories of eating habits and ethnic origins.

As I will elaborate below, the influence of the so-called thrifty genotype hypothesis on Japanese diabetology raises the question of how the mapping of genetic traits and the improving of lifestyle patterns actually perform the diversity of each other in practice. While this is almost a commonsense for both patients and caretakers in the hospital—or a technical obstacle that needs to be addressed in the design of a clinical trial—for anthropologists such interferences between differences is an attractive opportunity to explicate the complexity of comparison through empirical inquiry.

Michael Montoya (2007; 2011), for example, shows in his ethnographic account how genes and lifeways are folded into each other in diabetes research at the US-Mexican border zone, locally referred to as *colonias*. From the geneticists' field notes to DNA samples in the laboratory to the advertisement of diabetes drugs, the racial and social histories of Mexican immigrants living in the poorest regions of the American Southwest serve as both an explanation of and material for the understanding of the molecular mechanism of elevated glucose levels in the blood. Here, molecular explanations do not necessarily contradict more conventional epidemiological arguments on environment and lifestyle. It is rather the switching of scales across particular sites of knowledge practices that makes explicit such differences in their complex relations. In this process, what Montoya calls bioethnic conscription, "the social origins of human difference are folded in to a biogenetic or clinical claim" (2011: 194).

But while in Montoya's ethnography of genetic research it is the life conditions in the *colonias* that are "conscripted" into the daily practices of DNA sampling, in the adiponectin research, described below, it is the susceptible genetic pool of the Japanese that gives different ways of life the specific shape of a scientific fact.<sup>133</sup> It is this interplay among different logics of disease opened up by the thrifty gene—and later, as described shortly, enacted in the quest for the scientific underpinnings of adiponectin—that I try to highlight here. To understand how the explanation of one disease is measured through the variations of another, I explore the emergence of those differences as constitutive of disease itself by adopting a postplural approach.

### **3. The laboratory: experimenting with differences**

The molecular biology of diabetes increasingly came to be viewed as a domain in which public health concerns fused with pharmaceutical interests, and Kasahara's group had a pivotal part in this process. Their team in Tokyo was working day and night to identify the diabetes susceptibility gene he envisioned in the Sapporo conference, a gene that they were convinced they would locate by studying a hormone called adiponectin.

Adiponectin was discovered in 1995 in four different laboratories<sup>134</sup> around the world at the same time, immediately drawing the attention of the diabetes research complex as the most abundant transcript (mRNA) in fat cells, but its clinical relevance remained unclear for several years (see *Appendix 5-1*).

Because of its sheer volume, adiponectin's concentration in the blood was first thought to reflect the progress of obesity and insulin resistance in the body. The findings of the Kasahara group, however, took their colleagues by surprise. Contrary to most expectations, in their experiments on genetically

engineered diabetic (db/db) mice, insulin resistance correlated with the *reduced* expression of adiponectin; that is, when the body became less sensitive to insulin as a result of accumulated visceral fat, the amount of the hormone decreased (*Figure 5-2*). The formal publication of the group's study in *Nature* did not fail to underscore the fact that adiponectin appeared to be an anti-diabetic hormone (Yamauchi et al. 2001). The news section of the British medical journal *Lancet* made a similar point, calling it "a crucial link between obesity and insulin resistance" (Senior 2001).

By the time I visited Dr. Kasahara's lab at Hospital T in 2005, his team seemed to be a fair way along the path to tracking the genetic causes they so much wanted to isolate. I had just completed my fieldwork in a diabetes clinic and was trying to come to terms with the newest trends in diabetology, an effort that seemed to be hopelessly venturing into a level of complexity far beyond my initial expectations. Fortunately, and through some additional *nemawashi*<sup>135</sup>, I encountered Dr. Tanabe Kazunari, a physician and chief researcher of the Kasahara group. He became my genuine but sometimes terribly busy guide to the inner workings of both the molecular mechanisms of diabetes and the organization of his university lab.

Hospital T is an academic institution attached to a medical school in the middle of Tokyo. Clinical departments and the school are divided not only by a street but also institutionally. They run on separate budgets and different schedules, the only link between the two being the full-time faculty of the hospital, which is largely made up of the alumni of the medical school. Younger researchers, like Dr. Tanabe, not surprisingly, spend a great deal of their time with administration and patient care. Nevertheless, doing research—which, not incidentally, brings prestige to older professors—is key to advancing one's position within the hospital hierarchy.

Such a lack of clear division between research and patient care may seem unproductive from a strictly scientific point of view, but it may also facilitate the flow of people, information, and knowledge from one site to the other. When clinical research comes to the fore, as in the field of molecular biology during the past decade, such routes become more and more important and congested. So, while Dr. Tanabe's scientific interest was in molecular biology, much of his time was devoted to ensuring a smooth operation between genetic research conducted in the lab and a more routine kind of work treating patients at the hospital (which might seem at first glance far removed from genes indeed).

When I first met him in his tiny office in a remote corner of a run-down university building, I doubted for a moment whether he really was *that* Tanabe from the headlines of countless top-cited papers of international journals accumulating on my laptop. I was soon reassured, however, by his excellent overview of the current work done in his group and the scientific dilemma they were dealing with. He told me how he had developed his interest in the molecular mechanisms of diabetes during his graduate studies, when such topics had had little, if any, clinical significance: "I wanted to become a biologist, but in Japan that means you can't work on medical problems. If you ask me, I have no idea where to draw the line between my medical and biological interests . . . but this type of work on insulin secretion has drawn the attention of the industry, especially in the United States, of course, but also in Japan. So I ended up as a physician." This biographical fragment itself suggests that diabetes in Japan is constituted differently in biology and medicine when it travels through public and industrial pathways, as illustrated by the genetic experiments of the Kasahara team.

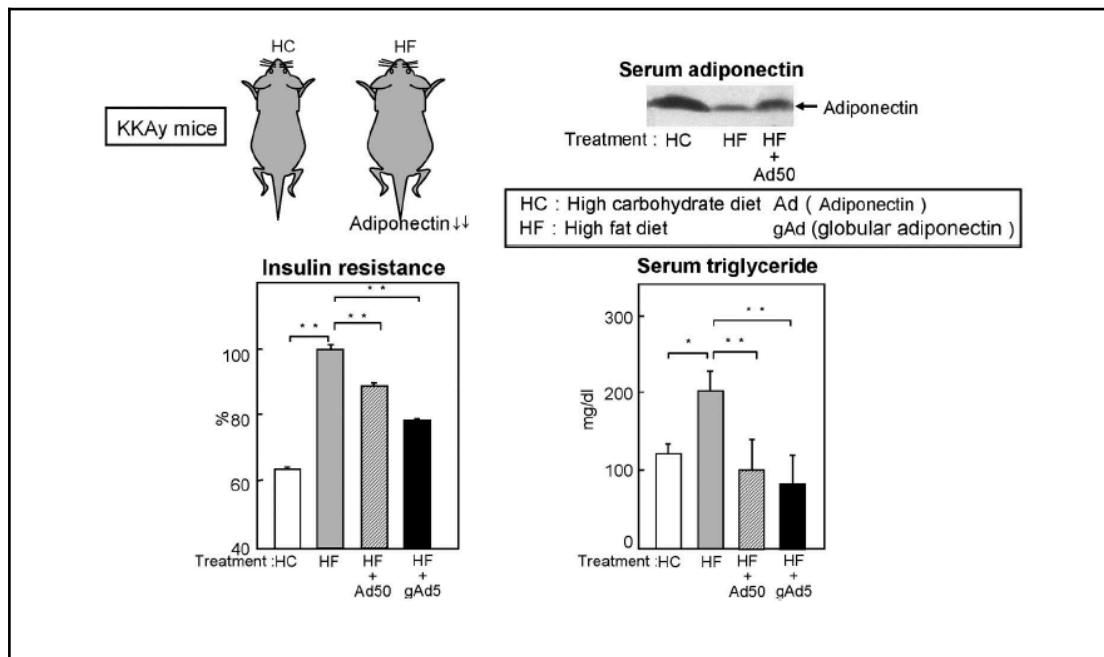
"The mouse model was a really big thing, because it was an *in vivo*

evidence of the cause and effect relationship between obesity and diabetes," Dr. Tanabe recalled. "But what made you think in the first place that it was a hereditary predisposition rather than the *consequence* of disease?" I asked, so used to hearing about obsessed gene hunters and the geneticization of medicine (Kato 2007; Lippman 1998). He looked surprised. "Well, ours is a lab of molecular biology, so we're looking for causes in the cell. *It's not necessarily hereditary, but that's how we try to find it.*"

Genes are not an end in themselves for diabetologists but a *method*, a method that stems from the practicalities of working with molecules and with molecular biologists. And while keeping in mind that genetics is only one of the possible approaches to complex disorders (and in Japan probably a less paradigmatic one than in the United States), it draws our attention to what we might call the biopolitical work of differentiation. And, as I will argue at the end of this chapter, political questions are, in the end, questions of method.

Researchers at Hospital H, in fact, were looking for several susceptibility genes and their variations at the same time, resulting in a complicated web of parallel stages of genetic work referring to and interacting with each other. The goal of attaining valuable genetic information through the screening of affected populations drew together researchers from around the world, a variety of patients of different backgrounds, pharmaceutical companies, and health administrators, among others. It was this constellation of heterogeneous elements and techniques around which functional consequences of the genetic expression of adiponectin were being crafted as the *risk* of the inheritance of diabetes.

The discussion I initiated with a notebook in my hand soon turned into a display of graphs, slides, and a long list of journal articles, leaving me no option but to give up taking notes. Dr. Tanabe showed me how they identified



**FIGURE 5-2** The adiponectin assemblage: animal tests

Animal tests suggested that adiponectin was an anti-diabetic hormone, and a possible target of drug development for human diabetes (Source: Kadowaki and Yamauchi 2005: 441).

TABLE 2 Comparison of genotypic and allelic distribution of SNPs between type 2 diabetic and nondiabetic subjects							
Polymorphisms	Genotypes [n (%)]			P	Alleles [n (%)]		P
	A/A	A/G	G/G		A	G	
-11414	A/A	A/G	G/G	0.37	A	G	0.59
T2DM	219 (57.0)	143 (37.2)	22 (5.7)		581 (75.7)	187 (24.3)	
NDM	275 (57.3)	187 (40.0)	18 (3.7)		737 (76.8)	223 (23.2)	
-11379	G/G	G/A	A/A	0.50	G	A	0.51
T2DM	367 (95.6)	17 (4.4)	0 (0)		751 (97.8)	17 (2.2)	
NDM	454 (94.5)	26 (5.5)	0 (0)		934 (97.3)	26 (2.7)	
-11365	C/C	C/G	G/G	0.25	C	G	0.10
T2DM	233 (60.7)	127 (33.1)	24 (6.2)		592 (77.3)	174 (22.7)	
NDM	265 (55.2)	178 (37.1)	37 (7.7)		706 (73.8)	250 (26.1)	
-4034	A/A	A/C	C/C	0.19	A	C	0.21
T2DM	327 (85.2)	56 (14.6)	1 (0.2)		710 (92.4)	58 (7.6)	
NDM	425 (88.5)	52 (10.8)	3 (0.7)		902 (94.0)	58 (6.0)	
-3964	A/A	A/G	G/G	0.03	A	G	0.49
T2DM	334 (87.0)	50 (13.0)	0 (0)		718 (93.5)	50 (6.5)	
NDM	429 (86.4)	47 (9.8)	4 (0.8)		905 (94.3)	55 (5.7)	
45	T/T	T/G	G/G	0.01	T	G	0.003
T2DM	164 (42.7)	169 (44.0)	51 (13.3)		497 (64.7)	271 (35.3)	
NDM	251 (52.3)	183 (38.1)	46 (9.6)		685 (71.4)	275 (28.6)	
276	G/G	G/T	T/T	0.007	G	T	0.002
T2DM	224 (58.3)	142 (37.0)	18 (4.7)		590 (76.8)	178 (23.2)	
NDM	236 (49.2)	203 (42.3)	41 (8.5)		675 (70.3)	285 (29.7)	
349	A/A	A/G	G/G	0.39	A	G	0.25
T2DM	172 (44.8)	169 (44.0)	43 (11.2)		513 (66.8)	255 (33.2)	
NDM	237 (49.4)	182 (40.0)	51 (10.6)		666 (69.4)	294 (30.6)	
712	A/A	A/G	G/G	0.42	A	G	0.98
T2DM	126 (32.8)	206 (53.7)	52 (13.5)		458 (59.6)	310 (40.4)	
NDM	168 (35.0)	237 (49.4)	75 (15.6)		573 (59.7)	387 (40.3)	
2019	D/D	D/I	I/I	0.69	D	I	0.41
T2DM	138 (35.9)	186 (48.4)	60 (15.7)		462 (60.2)	306 (39.8)	
NDM	182 (37.9)	232 (48.3)	66 (13.8)		596 (62.1)	364 (37.9)	

Numbers indicate the location of the SNP relative to the A of the ATG of the initiator Met of the adiponectin gene. D, deletion of nucleotide A at position 2019; I, insertion of nucleotide A at position 2019; NDM, nondiabetic subjects; T2DM, type 2 diabetic subjects. df = 2 and 1 for the distribution of genotypes and alleles, respectively.

**FIGURE 5-3** Sib-pair analysis

In the so-called sib-pair analysis, variations in the adiponectin gene were assumed to play an important role in the pathogenesis of type 2 diabetes (Source: Hara et al. 2002: 538).



the chromosomal regions where they expected to find the genetic factors of reduced adiponectin levels through a genomic scan of Japanese families with diabetes history.

The discussion I initiated with a notebook in my hand soon turned into a display of graphs, slides, and a long list of journal articles, leaving me no option but to give up taking notes. Dr. Tanabe showed me how they identified the chromosomal regions where they expected to find the genetic factors of reduced adiponectin levels through a genomic scan of Japanese families with diabetes history.

The initial step of locating human disease genes is called linkage analysis, which aims to identify the rough chromosomal location of genes that are passed down in families along the disease. Linked genes tend to be inherited in groups on a single chromosome, making such linkages the ideal targets of genetic research. These inheritance patterns may be easily traceable in monogenetic disorders, but they do not fit quite as easily with the complexity of diabetes. This is a common problem in multifactorial diseases, where numerous variables of environmental, genetic, and other variations overlap, and conservative linkage analysis is powerless to deal with such multiplicity. Type 2 diabetes, as I was often reminded by molecular biologists, is a complex disorder where not only environmental and genetic triggers are interacting to develop the disease but also multiple genes with related functions, having weak or moderate genetic effects on the susceptibility to hyperglycemia, are involved. Therefore, even acknowledging the multifactorial causation of this metabolic disorder is not sufficient to enable understanding its effects without attention to the variety of combinations of susceptibility genes in different families and different ethnic backgrounds. Here, methods other than genealogical tables may prove most useful for

identifying genetic causes.<sup>136</sup>

The Kasahara group's answer to this problem was a statistical platform called affected sib-pair analysis that helped them detect genetic factors of diabetes without an explicit model of its inheritance (*Figure 5-3*). They performed a genome-wide scan of Japanese type 2 diabetic families, assuming that common variations shared by these brothers and sisters will be found and might be associated with their disease. As Takahashi, a young bioinformatician in the laboratory, reminded me, their work was not gene hunting in the strict sense of the term, because there were no single genes to be blamed for diabetes. Looking for genetic variations in the expression of adiponectin in fat tissue was more like a part of a mapping process: their study of affected families was trying to locate natural variations in the genome that could be correlated with a "statistical *risk*" of diabetes. Such small samples, he told me, would provide the points of departure for bigger maps of the Japanese population, which in turn "would enable us to unveil complicated pathways of environmental and genetic risks and how they cause diabetes."

Adiponectin thus helped to perform the links between the health of the Japanese people and the concept of diabetes as a genetic disorder—given that these variables were considered merely in their fixed relation to one another. The underlying—though at first rarely voiced—problem, however, was that no algorithm existed for distinguishing *ethnic* differences of genetic polymorphism from *pathological* differences of disease. Such unaccounted-for interferences became all the more disturbing with human studies coming to the fore of the adiponectin research agenda.

During the early 2000s, a kind of competition unfolded among several laboratories around the world: they were testing different genetic mutations

in different population samples, making it increasingly difficult to distinguish genetic susceptibility to disease from "genuine ethnic differences," to use Tanabe's own words (*minzoku ni yoru chigai*). Scientists in Japan and elsewhere gradually realized that the understanding of how adiponectin affected insulin resistance was part and parcel of the design of their studies on how population differences come to signify genes and lifestyles.

The calculation between *ethnic* and *pathological*, for instance, may lie as well in methods of biostatistics as in the titles of articles. Kazuko, a graduate student working on adiponectin, told me about her concern with the way all her research was labeled as simply *Japanese*. "Look, these are my publications," she said showing me a list of articles each with at least ten authors, Kazuko being one among them. "All titles end with something like 'in the Japanese population.' Unless I write a review, all my work will be automatically labeled as 'Japanese.' I'm going to have a lot of trouble getting into a postdoc program abroad with such a list, don't you think so?"

The possibility that the efforts of molecular biologists result in a diabetes drug relies on the premise of genetic variation. Researchers are far from being ignorant of the fact that such variations have many layers, but sometimes it is beyond their reach to choose among them. As I learned later on, however, the notion of ethnic variation in the encoding of adiponectin was not only a model of diabetes, as rightly claimed by Kazuko, but also a model for making sense of the disease beyond the laboratory and the research community.

#### **4. Pharmacogenomic expectations and the problem of variation**

By 2004, the research on adiponectin was becoming part of an increasingly powerful public discourse: the bandwagon of pharmacogenomics. As I noted earlier, for Kasahara and his team the genetic research of adiponectin

underpinned a new era of order-made medicine, in which drugs and therapies would be tailored to individual genetic profiles. Such a testing of individuals for drug response is the ultimate goal of *pharmacogenetics*, a field of study that has developed around the problem of how genes affect individual responses to the same medication by looking for the genetic cause of differences in drug response. *Pharmacogenomics*, on the other hand, starts from the genetic differences within a certain population using whole-genome information to predict drug action (Roden and George 2002: 37).<sup>137</sup> So, while in the former case difference comes as a clinical fact (linking drugs and patients), in pharmacogenomics the emphasis in the development of new drugs is on epidemiological variation: the identification of ethnic, gender, and other group differences in symptomless at-risk conditions (Abu Ei-Haj 2007: 290).<sup>138</sup>

Such differences, it is expected, will lead toward the development of personalized medicine, envisioned in the talk of Dr. Kasahara at the Sapporo conference. The promise, therefore, is that postgenomic medicine is an extremely effective way to prevent the development—or, at least, the complications—of complex chronic conditions, such as high blood pressure, obesity, or diabetes, that affect large populations around the world. As such, its ability to mobilize powerful allies and resources that are themselves diverse is not quite surprising and has been thoroughly described in anthropological case studies from India (Rabinow 1999; Sunder Rajan 2006).

In Japan, it was oncologist Nakamura Yusuke who took the lead during the early 2000s in promoting pharmacogenomic research as a novel combination of scientific, public, and private interests. He became the head of the SNP Research Center that was established under the auspices of the Millennium Project at RIKEN, Japan's leading natural science research

institute. This position enabled him to supervise the Japanese component of the International HapMap Project, a consortium of public and private institutions in China, Nigeria, Britain, the United States, and Japan convened for the construction of a so-called haplotype map (see *Appendix 5-2*).

For pharmacogenomics, genetic variations are supposed to be *the* major factor for human diversity. As we have seen in the adiponectin work of the Kasahara team, mutations are claimed to provide insights into the genetic underpinnings of complex diseases. Changes in a DNA sequence in general—that is, among groups or populations—are referred to as *polymorphisms*, while supposedly individual changes are called *mutations*.<sup>139</sup> Although most genes reshuffle at the moment of conception, SNPs (single-nucleotide polymorphisms, i.e., single base mutations in DNA) on the same chromosome are inherited in sets, or so-called haploblocks, making it easier to map disease genes. It is this distinction between mutations and polymorphisms in general that collaborators of the International HapMap Project were hoping to mobilize.

Nakamura talked about this in an interview: "Before the HapMap era, we didn't have information about how different we are. But now, we have a set of SNPs that can be used in large-scale genetic studies aimed at finding disease susceptibility genes or drug-response-related genes. The information should be applied to the development of novel therapeutic tools, and also for preventing disease or preventing disease progression" (Bonnen 2005: 1).

Allocations leapt in 2003, when the SNP Research Center at RIKEN obtained the support of the Ministry of Education, Culture, Sports, Science and Technology (MEXT) for the the "Personalized Medicine" project, which clarified its aims in four points: genetic analysis, genetic mapping, drug development and public health screening (see *Appendix 5-3*). To achieve these

goals patients in participating institutions were requested to provide blood samples to be stored in tubes in liquid nitrogen and clinical information in a form of a questionnaire on lifestyle and medical records. The database, it was argued, would facilitate the exploration of the connections between such genetic pedigrees and environmental variables with statistical methods.

By 2008, the so-called "Biobank Japan" managed to gather DNA, sera and clinical information from more than 200,000 patients with either of 47 common diseases diabetes being the second most common on the list following cancer (*Figure 5-4*). Given the sensitivity of the Japanese public regarding the issue of blood after a series of scandals of contaminated pharmaceutical products during the past two decades, one would expect a debate on and criticism of the building of such a database. What is intriguing however is that ethical discussions have been focused on questions at the practical level, such as the use of informed consent rather than the ethical and political consequences of the involvement of industry. A remark in the FAQ section of the project's homepage may shed some light on how the notion of 'personalized medicine' establish an altruistic link between the citizen and the market:

Q: To my knowledge, private sector may obtain information. What are the concrete forms of such information transfer? I assume that providing such information to pharmaceutical companies would enable them to make profit for themselves, wouldn't it?

A: [Yes,] pharmaceutical companies and medical suppliers may obtain information [from the database]. Their revenue will be reflected in the development of new drugs and diagnostic technologies, so patients will be profiting too. Moreover, companies pay their taxes after such profits thereby contributing [directly] to the [support of] the state.<sup>140</sup> (Biobank Japan 2005a; translated by the author)

While Biobank Japan bears the hallmarks of similar registries around the world (Gottweis and Petersen 2008), its self-proclaimed goal of 'personalized medicine' under a completely public model distinguishes the Japanese project from most other cases. In this novel arrangement, individual differences targeted by pharmagenomics and the expanding biotechnological industry were feeding into the homogeneous diabetes-prone Japanese population echoing Kasahara's vision of 'order-made medicine.'

While the International HapMap Project itself was not focusing on any specific disease, it was a public endeavor for supplying genetic information about variation to researchers. This information, it was assumed by the initiators of the project, would help to overcome the hardships of differentiating between ethnic and pathological variables that made small-scale studies like that of adiponectin virtually impossible, as mentioned earlier.

Such genomic maps of human variation, it was argued, would lead to the development of new diagnostic techniques and "order-made treatment," a buzzword often evoked by Kasahara himself, who smartly used the media to project his research into the logic of pharmacogenomics.<sup>141</sup> In an increasingly volatile pharmaceutical landscape, the slogan of "order-made medication" resonated profoundly.<sup>142</sup> And although the message of individualization was part of this idea, the Japanese formulation of the phrase drew also heavily on an imaginary of disease that threatened Japanese people and demanded Japanese drugs.

Clearly, from such expectations, the relationship between molecular biology and epidemiology is part and parcel of the comparative practices that are necessary to develop new medications. The following brief story will highlight how it is actually done.

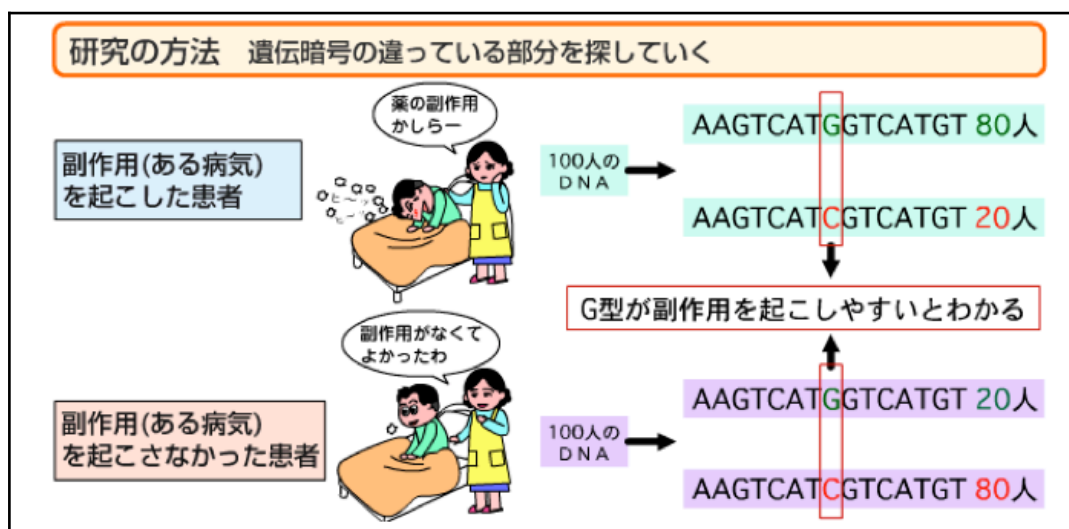


FIGURE 5-4 Different genes, different drugs, different people (Biobank Japan)

This online booklet of the Biobank Japan Project explains the way researchers try to find the links between genetic coding and the individual differences in drug response. (Source: Biobank Japan 2005b)

**In type 2 diabetes many body parts are involved**

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The insulin sensitizer that delivers:<sup>1</sup>

- effective glycaemic control
- positive lipid benefits, and
- once daily dosage.

Reference: 1. Aouf et al. Pooled analysis of the efficacy and safety of pioglitazone in the treatment of patients with Type 2 Diabetes Mellitus. Diabetes Care 2004; 27: 1000-1005.

Reference 2: Metformin. Each tablet contains 500mg of hydrochloride equivalent to 400mg of metformin. Reference 3: Glipizide. Each tablet contains 5mg of glipizide hydrochloride equivalent to 4.5mg of glipizide. Reference 4: Glipizide. Each tablet contains 5mg of glipizide hydrochloride equivalent to 4.5mg of glipizide. Reference 5: Glipizide. Each tablet contains 5mg of glipizide hydrochloride equivalent to 4.5mg of glipizide.

**NEW actos pioglitazone HCl**

Each tablet contains 15mg of pioglitazone HCl.

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**Lilly**

FIGURE 5-5 Different body parts

The variety of complications diabetes brings about become visible in the multiple effects of the drug on affected body parts. Source: Advertising material of Actos® circulated in the U.S. by Lilly Ely Co., 2007.



## 5. Pharmaceutical values: the case of glitazones

Interestingly, a recurring argument for the hypoglycemic action of adiponectin—which Dr. Kasahara and his team were trying to pin down—has come from the fact that TZDs (thiazolidinediones, or glitazones), a new class of anti-diabetic drugs, were reported to raise adiponectin levels in the blood (Yu et al. 2002). The development of glitazone was initiated by the Japanese pharmaceutical giant Takeda in the 1970s in its effort to create more potent anti-diabetic drugs than those on the market. The team published its findings in 1983, generating considerable excitement in the pharmaceutical industry, although no one knew how the compound actually worked. It took a decade and a long journey from Osaka to North Carolina to answer this question. By 1994, scientists at the Glaxo Research Institute were able to show that glitazones activated PPARs (peroxisome proliferator-activated receptors), a group of receptor proteins that play a central role in glucose metabolism by regulating gene expression (Patlak 2002).<sup>143</sup> The first actual TZD drugs came on the market in 1999 under the brand names Actos (Takeda) and Avandia (GlaxoSmithKline), holding out the promise of the prevention of diabetes (see *Appendix 5-4*).

The reason that I went into such detail about the genesis of TZDs is that they turned out to be an important building block in explaining the action of the adiponectin gene in diabetes. In 2005, a comprehensive clinical study investigating the effectiveness of TZDs in the prevention of cardiovascular events was being completed in Europe. The PROactive study was a clinical trial sponsored by Takeda and Lilly—the manufacturer and North American distributor of Actos—which were hoping to expand its market beyond diabetes patients (*Figure 5-5*).<sup>144</sup> The trial was conducted in several hospitals across Europe, enrolling diabetes patients with cardiovascular disease. They

were then randomized into two groups to compare the effect of the medication on cardiovascular events during the three years of the trial. One group received the medication, while participants in the control group were given placebo capsules of the same amount. In addition, both groups were allowed to continue their existing treatment.

In this peculiar setting, diabetes emerged as the scale for the comparison between therapeutic intervention and placebo, but only as long as it was measured against the risk of cardiovascular disease. As it turned out, pioglitazone reduced the risk of heart attack and death overall, on the one hand, while raising the risk of heart failure, on the other, leaving investigators with more questions than answers. Contrary to expectations, diabetes and cardiovascular disease did not emerge parallel from this study; rather, the medication showed that they are connected in their differences.

At the same time, laboratory experiments of Kasahara's team and another group in Osaka were indicating that adiponectin levels could be associated with a much wider variety of conditions than originally had been thought, pointing to the same result as the PROactive study through a different type of evidence (Yamauchi et al. 2007). While the in vitro models demonstrated that receptors targeted by the TZD drugs (PPARs) are deeply involved in the metabolic action of adiponectin at the molecular level, the clinical data, in contrast, indicated that these drugs were viable candidates for the reduction of cardiovascular risks in some cases. Thus, while it did not offer a direct route from genes to drugs, adiponectin brought molecular biologists into the fold of public health and industrial research by eliciting important relationships among remote sites of difference:

Adiponectin is an adipokine that exerts a potent insulin-sensitizing effect by binding to its receptors such as AdipoR1 and AdipoR2,

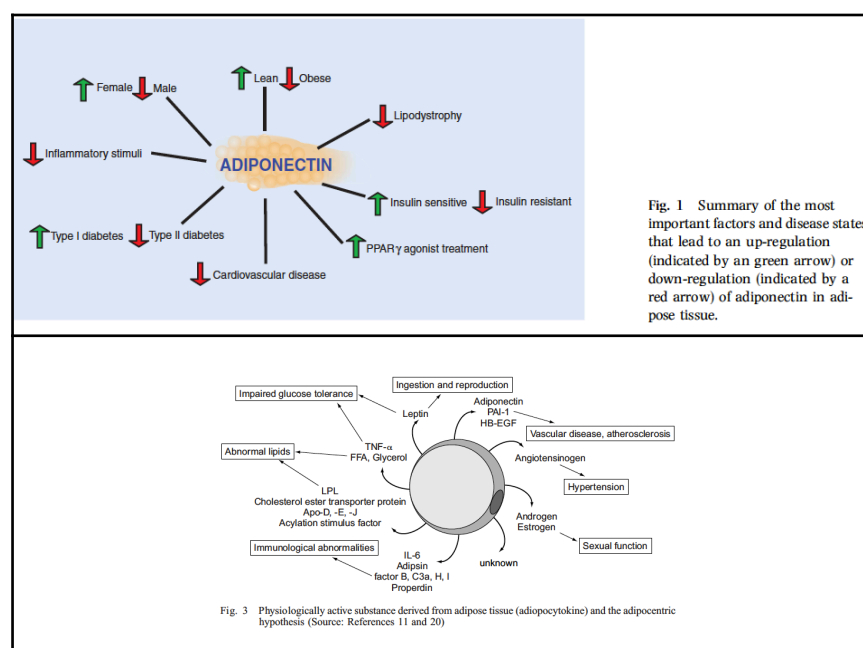
leading to activation of AMPK [activated protein kinase], PPAR $\alpha$ , and presumably some other unknown signaling pathways. Indeed, circulating levels of adiponectin, especially HMW [high-molecular-weight] adiponectin, are positively correlated with insulin sensitivity and altered by various genetic and environmental factors, pathological conditions, and medications. Thus, *monitoring the levels of HMW adiponectin is a good predictable marker for type 2 diabetes and the metabolic syndrome. Moreover, methods to increase adiponectin levels, such as TZD administration, are expected to be effective for the treatment of these diseases.* In the future, enhancing or mimicking adiponectin action through modulation of expression and/or function of the adiponectin receptors may be a novel and promising therapeutic strategy for insulin resistance, type 2 diabetes, and the metabolic syndrome. (Kadowaki et al. 2006: 1790; emphasis added)

As I elaborated in the previous chapter, the term metabolic syndrome has come to assume an increasingly central position in Japanese discourses on public health issues as a new technology for producing evidence about the cardiovascular risks of diabetes, hypertension, and obesity. For diabetes experts and public health officials in Japan who were deeply embroiling themselves in the controversy around the ethnic and gender differences of waistlines and their meaning for the risk of cardiovascular complications, the adiponectin research held out the prospect of a scientific justification of metabolic syndrome.

In spite of (or, rather, because of) the controversies surrounding the metabolic syndrome, the so-called adiponectin hypothesis became substantiated by clinical evidence. Two separate assumptions have been welded together in this hypothesis: (1) that, contrary to current theories, diabetes has indeed a fundamental, if not single, genetic cause and (2) that the search for such cause would eventually lead to drugs that can treat diabetes. The former assumption indicated that the genetic expression of adiponectin

influences insulin resistance and could potentially serve as the biomarker of underlying metabolic complications and cardiovascular risks. If there were enough evidence that this marker showed ethnic differences, the second assumption held, such differences could possibly serve as the *molecular target* of personalized drug design in the future.

Given its lack of specificity, adiponectin provided convenient links among disorders from atherosclerosis to obesity, and so, too, it offered a platform where the different interests of physicians and pharmaceutical companies could meet. The adiponectin research thus became a driving force in establishing links among public funds, academic science, and industrial interests through the important differences between diabetes and cardiovascular risks (Figure 5-6).<sup>145</sup>



**FIGURE 5-6** The adiponectin assemblage: linking domains

As adiponectin traveled from the laboratory to the public domain, its chemical substance became an important link between differences of various kinds. (Sources: Matsuzawa 2002: 107 (below); Trujillo and Scherer 2005: 170 (above))

## **6. Interferences: the adiponectin assemblage**

Reflecting an increased concern with prevention and risk, the place of diabetes in Japanese health care has been transformed in considerable ways in the past decade, and molecular biology played an important part in this process by affording both a technological platform for public health and the promise of personalized medicine. Until recently, risks associated with high levels of glucose in the blood were a concern for epidemiologists rather than molecular biologists, and most forms of diabetes have been framed as lifestyle-related or autoimmune conditions in the popular imagination in Japan. However, although genetic work is likely to be done in laboratories with mice and microscopes, whereas epidemiologists study human populations on statistical tables, the objects of these two kinds of research are entangled in the case of diabetology, giving way to new and original differences. To be sure, in addressing these pharmacogenomic visions and their political and clinical implications, my aim was not to make a case for or against genetic and epidemiological arguments. Rather, I wanted to shed light on the specific dynamics of their relationship in Japan.

Dr. Kasahara and his colleagues realized early on that the localization of genetic variations affecting diabetes along ethnic differences had its implications for national agendas of health policy and the global reorganization of the drug market. His team—along with others around the world—showed that genetic variations are indeed responsible for reduced levels of adiponectin, contributing to certain forms of insulin resistance associated with obesity. As these results traveled from the Osaka laboratory to North Carolina, their implications have been substantiated by clinical evidence in the trials of the PROactive study—in European hospitals—that had been designed to compare the health hazards of diabetes and

cardiovascular risks.

Should this intricate interaction between science and industry be understood as a new form of epidemiology? This is what Andrew Lakoff (2005) has put forward concerning pharmaceutical companies' collection of audit data on patients in Argentina and the United States. He writes: "As a form of knowledge about health practices that is used in guiding expertise, pharmaceutical audit data emerge as a kind of 'neoliberal epidemiology.' . . . These numbers provide a vision of the territory as containing a market rather than a population" (199–200). And while the pharmaceutical privatization of life indeed has far-reaching implications for the shaping of moral and scientific orders in various parts of the world,<sup>146</sup> it does not square well with the heterogeneous assemblage of adiponectin. While in the former case the movement seems to be toward some form of closure (medicalization, profit, etc.), the mobility of an assemblage depends on its instability (Verran 2009).

To make sense of Strathern's claim outlined at the onset of this chapter—that difference is a form of relatedness—we may turn the above critique on its head by insisting that it is the very epidemiological mode of comparing ethnic differences, genetic variations, and disease patterns that folds markets and populations into each other in novel ways. The analytic purchase of this postplural move resides in the possibility to reclaim the openness and indeterminacy of a politics in practice that has been put off by critiques of neoliberalism and medicalization (see e.g. Healy 2012).<sup>147</sup>

Ethnic, gender, and pathological variations exist in their multiple relations, or, to borrow Donna Haraway's (1997) term, they *interfere* with one another. The concept refers to waves that collide with each other and diffract in different patterns (*Box 5-1*). This consideration indicates that differences are mobilized and articulated in the situations where they meet each other and

that empirical research should focus on the locations of such encounters. Furthermore, as has been suggested by others, it is in such encounters among disparate kinds of things that scientific questions become political acts, and political problems turn into scientific evidence. Rather than one being imposed on the other, the contents of both are established in the technosocial practices that link them (Moser 2006).

Recognizing such interferences poses the question of how different orderings of the world and the realities they perform hang together:

Often it is not so much a matter of living in a single mode of ordering or of "choosing" between them. Rather it is that we find ourselves at places where these modes join together. Somewhere in the interferences something crucial happens, for although a single simplification *reduces* complexity, at the places where different simplifications meet, complexity is created, emerging where various modes of ordering (styles, logic) come together and add up comfortably or in tension, or both. (Mol and Law 2002: 11; emphasis in the original)

It is in this sense that we may speak of comparison as an actually existing instance, which allows insight into the situated ways differences among (id)entities emerge through multiple kinds of relation each bringing with it its own particular (and partial) logic of knowing the world. As the case of adiponectin shows, these partial perspectives of epidemiological, genetic, and market realities engage in an ontological politics through interfering with each other in the work of comparison.

What are the differences of developing risk of diabetes (type 2) between Japanese and other people if they are the results of neither biological variation nor culturally diverse understandings of disease? Scientific notions of genetic

risk, as well as anthropological ideas about the multiplicity of perspectives, rest on the strong pluralist assumption that cultures or genetic traits are comparable *because* they do not interfere. This logic, however, contradicts with the logic of adiponectin.

In attempting to make sense of the working of adiponectin, experts have to assess the specificities of difference with and similarity to other things and practices. A series of incommensurable parameters—waistlines, glucose levels, drug prices, SNPs—have to be conjoined and separated in the process of comparing genes with populations, populations with markets, and markets with genes. In these comparisons, adiponectin emerges in multiple forms that contain and shape each other: a hormone, a gene, a protein, a marker, and sometimes even a person that substitutes for the self in preventing diabetes. In other words, the heterogeneous assemblage of adiponectin that I described in this chapter is neither a premise (as most molecular biologists would claim) nor an a posteriori construction (as anthropologists might assume) of the differences between the Japanese and other populations, cultures, or markets; rather, it is brought into form in and through a strong relationship with the idiosyncrasies that it stands for. Difference, here, signifies a fluid process, partial connection, rather than a constant quality—identity, race, and so forth. Adiponectin, one could say in a postpluralist logic, is composed of the differences that it connects: it acts as its own scale by comparing itself (Holbraad and Pedersen 2009: 375).

From an anthropological point of view, the fact that multiple explanations of elevated sugar levels coexist provides not only a *ground for* but also a *tool of* comparative work. It also implies that differences (and similarities) are not necessarily external to comparisons, as a pluralist mode of analysis would suggest, but are also composed of them. Disease here is a



discrete entity of knowledge or experience only as long as it enters into relations and undergoes transformations through the assemblage of pharmacogenomics concern.

The particularity of diabetes, I have been arguing, emerges from the differences it puts into contact. The comparative practices that have been described above do not rely on a single condition (or its medication), which would allow for any easy calculation of health or financial risks and benefits. Along with and in relation to different genes, drugs and populations come different political cultures of science and multiple realities of disease that keep dissolving and combining with one another in new ways. It follows from this that audit data and scientific facts are but two, albeit powerful, kinds of objects in the complex web of pharmacogenomic assemblages. What is a prospective commodity for a Japanese company on the other side of the ocean may foster more effective public health interventions in Japan. A technology that helps to detect racial or ethnic difference in a laboratory today may be an answer to the global epidemic of diabetes tomorrow. The three different phases of the adiponectin research that have been told here neither oppose nor foster neoliberal strategies of privatization or pluralism. They rather contain them through the comparative endeavors that travel among technoscientific, political, and medical realms.

## CHAPTER SIX

### Communities of Disease

*in which stress and high glucose levels are compared and patients emerge as a collective*

*Incommensurability implies neither sealed language games nor full integration, but invites ongoing conversation as each side interprets the other.*

—Michael Lambek

The previous two chapters traced a relatively new attention to human differences in biomedical and public health interventions of diabetes. While transnational genetics, along with pharmaceutical business strategies, locate ethnic and racial variation on the molecular level, those identifiers articulate specific concerns of epidemiological research about the inclusion of differences and inequalities in the assessment of health risks and the prevention of diabetes. I hope to have shown through the inquiry into these two different modalities of research that the effects of diabetes—genetic biomarkers and public health concerns—emerge out of hybrid alliances between human and nonhuman entities. Such effects, however, may be blocked when they are gathered up as an embodied experience in a collective that brings new configurations of disease into play.

To continue to explore the embodied mediation of the multiplicity of diabetes, I will focus on the activities of a patients' advocacy group in Eastern Tokyo that I will call the *Kuromatsu-no-kai*. Their claim of collective identity around the shared experience of chronic illness reveals a dynamics whereby living with diabetes keeps connecting and splitting personal and political realms. The question here is how and why these two radically different

horizons of diabetes are aligned (or not) in the emergence of new communities who now increasingly intervene into the treatment and prevention of chronic disease. The immediate aim of this chapter is to shed some light on the changing nature of lay intervention in medical care, and, more specifically, the mobilization of communities in health promotion and disease prevention. In so doing, I will consider the work of translation in which the knowledge of blood sugar as provided to us by modern medicine and the subjective forms of human suffering come to posit each other in hybrid events such as the comparison of flavors and calorie intakes in the self-help group and the marketing of health products, more generally. I will call such situations *technosocial commensuration* in order to indicate the complexity of comparative practices in contemporary healthcare.<sup>148</sup>

## **1. The old-new politics of patient advocacy**

The active participation of patients in medical research in Japan long precedes the current movement of lay involvement into medicine and the healthcare system. In the 1950s, it took the painful experiences of fishing families in Minamata and some enthusiastic young researchers at Kumamoto University to prove the link between industrial activities of a metallurgical enterprise and the health catastrophe that killed many hundreds of people and left thousands more disabled (see e.g. George 2001). The co-production of lay experience and expert knowledge in medicine gained on additional meaning in the following years as a direct consequence of the grassroots activities around environmental pollution (*kōgai*) and medical contamination (*yakugai*). Given the difficulty of managing uncertainties related to the proliferation of socio-technical arrangements such as universal vaccination or organ

transplantation, this newly emerging patient activism has been a dual concern for Japanese politicians and bureaucrats, both specifically as a welfare challenge and more broadly as a new form of public participation (see e.g. Cullinane 2005; Inose 2017; Yamazaki 2015).

The emergence of other, less visible, advocacy groups in postwar Japan have been predicated upon the logic of identity politics that arose from these struggles: challenging professional (i.e. political, scientific, etc.) monopolies through the articulation of a collective identity. This has required intimate mediations between shared experience and the established facts of specific health conditions. In some cases, it took the form of a turn towards science by directly engaging in medical research and applications. This has been a common configuration in so called orphan diseases (*kibyō*) and incurable diseases (*nanbyō*) that had to be made socially visible to propel scientific research.<sup>149</sup>

But as described by Karen Nakamura on the example of The Japanese Federation of the Deaf, there have been another strategies for promoting the interests of patients through symbiotic relationships with the state. She writes as follows: "This amoeba-like ability to spawn off subgroups that engage the government at different levels is what one JFD leader termed 'participatory welfare' (*sanka fukushi*). That is, rather than viewing welfare as manna from heaven (...) this leader felt that the Japanese deaf community must engage directly in welfare and participate in its creation and execution (Nakamura 2002: 30). This model of coordination is strongly linked to the chronic nature of disabilities and diseases around which these groups have been formed. We may say that it is also the pattern followed by many small diabetes self-help groups affiliated with hospitals and health centers around the country and their umbrella organization, the Japan Association for Diabetes Education and

Care (JADEC). But not *Kuromatsu-no-kai*, the focus of the following two sections.



**FIGURE 6-1** Map of Tokyo (East) showing Kōtō-ward and Sunamachi

Source: Wikimedia Commons, [https://commons.wikimedia.org/wiki/File:Tokyo\\_maps\\_file.svg](https://commons.wikimedia.org/wiki/File:Tokyo_maps_file.svg) (accessed on August 16, 2017)

## 2. "No doctors here:" The *Kuromatsu* Patient Group

The *Kuromatsu* Patient Group (*Kuromatsu-no-kai*) is a self-help group that brings together people with diabetes and their families in the Sunamachi area of Kōtō-ward (see *Figure 6-1*). It is a blue-collar neighborhood in Eastern Tokyo, a fifteen minutes train ride from the centers of the city, sitting on a land that has mostly been reclaimed from the sea since the Edo period.<sup>150</sup> Sunamachi shares most of its history of industrialization and disasters with

the surrounding neighborhoods that are collectively referred to as "Shitamachi" ("low city"; literally downtown) by Tokyoites conjuring up nostalgic images of communal harmony and bustling shopping streets (see *Appendix 6-1; 6-2*).

On my initial visit to the public health department (*hoken jo*) of Koto Ward in 2005, Shindo-san, who was in charge of the diabetes prevention program, showed me old photos of the neighborhood. One was a *nagaya*, a long wooden house in which extended families used to live together. At first, I was at a loss given the fact that I came to collect information about the health policy of the ward, but he didn't hesitate to explain what caused him to come up with this brownish, vintage photo. "As you can see, people lived together in such houses, they passed down eating habits and herbal remedies from generation to generation enabling them to prevent many ailments that we, modern folks, cannot cure. What we are trying to do here, in the center, is to recreate such communities through health promotion. So, you can say, that in a way, we just change the course of action."<sup>151</sup> The image of the *nagaya* has become deeply imprinted into my ethnographic perception in the course of my subsequent discussions with Shindo-san and other health officials, although I have never been into one where people actually lived. But it was a vision that exploded many of my abstract conceptions about welfare and public health and became an orienting framework throughout my work with the members of the patient group in Sunamachi. It seemed to me that the logic underlying the diabetes program was a need to reach out not only to individual patients but to civil society, and if such did not exist then to help them to organize themselves through their shared experience of disease.

The *Koto Ward Diabetes Program* was part of larger project called *Kenko Nippon 21* (Health Japan 21), the national public health strategy, which started

in 2000 and was co-financed by the local government. It was coordinated from the health department of the ward by two officials, but most of the actual operation was carried out at five local health centers (*hoken sentā*) by social workers and four physicians employed on a voluntary basis. As Shindo-san explained to me on another occasion, the diabetes prevention action plan had four specific components: (1) prevention (e.g., free check-up services), (2) education (diabetes workshops, dietary advice, etc.), (3) collection of statistics, (4) empowerment (fostering of communication between experts and patients).<sup>152</sup> I admitted that I had my doubts regarding the efficacy of the latter and told Shindo-san what I had seen in hospitals, where such communication was often mediated in practice by small technological devices and tools of care. But he didn't seem to be convinced. "Patients have a lot of practical knowledge to share," he replied, "and it's very difficult to put them into conversation with doctors in a clinical setting. We organize patient-doctor meetings at the [health] center to create forums where people with diabetes can publicly discuss their problems." I must have still seemed unconvinced for he added: "I understand your skepticism, but I tell you that these are the first building blocks of a new and truly local healthcare strategy." The point was that the grounded knowledge of chronic disease could mobilize civil society. Through prevention and treatment, the diabetes program impressed a specific shape on the relations between the state and the collective of citizens to embody and articulate differences of scale.<sup>153</sup>

It was during one of these early meetings that Shindo-san introduced me to Nakamura-san, a social worker who was appointed as the coordinator of the activities of the diabetes self-help group at one of the local health centers of the ward.<sup>154</sup> She was a young woman in her thirties, wearing a white coat and browsing through a stack of files on a shelf full of colorful information

booklets, administrative guidelines, government bulletins and other official documents when we first met. "Here it is," she turned to me holding a thick dossier in her hands. It contained the progress reports of the activities related to the self-help group. "It's called *Kuromatsu-no-kai*," she said with a very sharp (or maybe bored?) look at me. "They have something like 25 members. Mostly elderly people from the neighborhood. I help them to organize cooking lessons once in a while, or set up events like walking in the park together. We have a one-week diabetes workshop each year at the health center, where we invite some of the members to talk about the difficulties of their daily regimens."<sup>155</sup>

*Kuromatsu-no-kai* grew out from such a small training workshop at the health center in 1997. Since then, it had benefited a great deal from the support of health authorities, which helped the group to gain official status by the approval of the local medical association (*ishikai*). From then on, the maintenance of its activities, the infrastructural background and the planning of individual projects and annual schedules have been closely tied to the local health center—a fact that some members continued to harbor concerns about, as we shall see below. They preferred to see their group as an independent organization founded on the recognition of the distinction between expert knowledge and lay experience of disease.

During the following years I participated in the monthly meetings of *Kuromatsu-no-kai*, where I found, among others, friendly chats about the newest *kampo* medications (and why physicians refuse to prescribe them) and heated discussions over an official invitation to the national federation of diabetes self-help groups, which some members rejected flat out. One overwhelming concern was how to reach a common ground that would be more than the adoption of expert clichés about strict control, but less than a



cacophony of lay voices.<sup>156</sup> This emergent configuration of local communities and diabetes reminded me of the *nagaya* that had once extended along the narrow alleys of Shitamachi as monuments of familial unity penetrated by the differences that connected its residents to the outside world. Technocrats, doctors and community leaders similarly connected the risk of diabetes with lay expertise and state institutions in the activities of cooking, walking and learning.

Tellingly, however, members of the *Kuromatsu-no-kai* eventually distanced themselves from the popular health movement by rejecting the public space that had been dominated by moral questions of self- and community empowerment. And although some of them attended hospital-based patient groups, as well, they by and large found the clinical framework morally demanding and overly restrictive. So, while Shindo-san at the health center praised the program as a joint action between civil society and local government, Murata-san, one of the founders, expressed his doubts about such collaboration and put the emphasis on the separation between governance and advocacy. As he recalled the early years of the association, he was very explicit about such distance from both technocratic values and medical professionals: "I was always nervous in front of the doctor and the five minute-examination at the clinic didn't help much to get rid of that tension. I felt paralyzed...And then I first attended this training program at the *hoken-jo* and it just gave me a different sense of the disease in me. We cooked together and enjoyed the meal that we prepared together. We shared our food at the table and our stories of struggling with diet restrictions. I kind of forgot that we were there for the disease. And then we decided to gather again, and again to learn about diabetes. We formed this little learning group (*benkyōkai*). Well, I say 'learning,' but, you see, there are no doctors here, we

don't need them; we are all patients, we eat together, and we learn about diabetes in our own way."<sup>157</sup>

The very existence of *Kuromatsu-no-kai* was questioning the empowering rationale of grassroots health activism and a public acknowledgment that the political relevance of diabetes could be obtained only through personal configurations.

### **3. Eating together 1: *gaman***

Eating became a way of learning diabetes, an event of appreciating and comparing disease. Food, drink, and the acts of preparing and consuming them extended to the core of each patient's being providing a way to express suffering and distress in situations of knowing about the disease inside their bodies: "What's the time? Oops! My insulin peaks soon...I'm going to go grab something for lunch. Will you join me?" Such kind of daily stress was a condition that followed blood sugar levels. The self-help group entered into this space of disease by crafting new configurations of engagement with food from organizing cooking days around particular themes (like '*bentō*', 'Chinese', 'soup', etc. ) to inviting chefs from a hotel or sales representatives of catering services specializing in diabetic food delivery. These events connected them to things (food and else) they had never seen or done before by prompting them to take the painful aspects of living with diabetes as an access to knowledge.

Eating-out in a restaurant once a year was one such an event. At the meeting<sup>158</sup> which preceded the annual restaurant gathering members prepared a small memo with simple entries on it, like "salt, oily food, dietary fiber, balance", etc. At last, all members wrote the following sentence at the top right corner of the paper: "Let's enjoy food!" No question, it was at this point where food became a common sense of the anxious metabolism. The

food prepared by someone else was the predicament of diabetes by the simple fact that its energy intake was hard to estimate. According to Takamura-san, a retired taxi driver,<sup>159</sup> such a dilemma was only partly due to an administrative failure of enforcing the display of calorie count labels in public eating places in Japan; it was also, and probably more importantly, a practical consequence of having people eating together, which made them eat more, especially when they shared a whole table of food in a Japanese-style dinner. As Takamura-san put it very aptly, he cared less about calories and more about people, which made every single eating-out occasion a somewhat traumatic event for him.

However, for many diabetes patients and their families "sociability is not simply a way of encouraging eating: it is also an end in itself for which eating and drinking provide the means" (Harbers et al. 2002: 216) This collective experience of disease was important for women like Takagi-san who performed their public role as caregivers through preparing and measuring food. She wasn't sick herself, but attended the meetings on behalf of his husband who couldn't actively participate in the weekday activities because of his work. As she put it: "I do the cooking anyway! He could learn nothing here even if he had the time to come."<sup>160</sup>

Such a view of food may seem akin to what anthropologist Anne Allison observed as the effect of 'education motherhood.' In her study of mothers who prepare lunch-boxes for their children at Japanese daycare centers Allison found that food practices embedded family bonds in a web of power relations from the collectivity of pupils to institutions of the state by blending personal discipline and collective life (*shūdan seikatsu*) so that everyone is expected not only to eat correctly but also to eat correctly as a member of the group (Allison 1996).

And while eating was indeed both a beginning and an end of the

collective, it had to get through some calculation before it could be shared as an experience of disease. Food figured as an important event of patient advocacy in the act of counting calories. The move, then, was away from *food* and toward *nutrition*. Nutrition was not a premise of health advocacy dancing in the heads of epidemiologists and bureaucrats; it was coming into being in the enactment of blood sugar levels that changed according to the amount and types of food consumed and the daily management of their balance.<sup>161</sup> Such calculations have been the work of professional nutritionists and nurses until recently (as we have seen in Chapter 2), but thanks to a simple printed catalog of foodstuffs, now it was changing into a means of estimation done by diabetes patients themselves. The daily practice of calculation that was made possible by this so-called *Food Exchange List* and other tools of measuring reconfigured the simple routine of "eating" as an act of knowing and articulating nutrition levels.

*Kuromatsu-no-kai's* spring meetings were held in a park close to the health center where members were regularly gathering. It was scheduled for the first week of April, which, if all went well, coincided with the flower-viewing season, thus providing an occasion for preparing and enjoying *bentō*, or boxed-lunch, together under the blossoming cherry trees—a traditional activity of urban Japanese called *hanami* and practiced by hundreds of thousands of Tokyoites each year.

Before the main event, seven members of the group got together in Murata-san's house, which stood between an old abandoned brick factory and a *danchi* (apartment complex) on the other side of the road.<sup>162</sup> All participants arrived with the *Food Exchange List* in their hands and Murata-san's wife arranged tiny scales for everyone to measure the weight of the foodstuffs (see Figure 6-3). Another woman bought three kinds of *bentō* at a nearby

department store, and now she was busy with emptying their various contents upon a long table on the tatami mat surrounded by group members. They put each food item on the scale and wrote down their weight on a piece of paper. Next, these numbers were transcribed to the blank columns of a printed list prepared by Murata-san's son a couple of days earlier. It was this "Calorie Counting Chart" (*karorī keisan hyō*) that made nutrition and food speak about the same object through measuring, estimating and comparing (see Figure 6-2). This process of translation, however, was far from being smooth; it was a remarkably demanding and stressful task, as we will see in the unfolding events.

4月花見 升本「香取弁当」カロリー計算表(平成18年)

2006/3/27(月)

献立	材料名	分量(g)	表1	表2	表3	表4	表5	表6	調味料/嗜好品	合計 (単位)	合計のkcal	1人分のg数
香取弁当	ご飯	170g	3.40							3.40		ご飯50g
	煮豆	13g			0.23					0.23		煮豆67.5g
	鮎	21g			0.44					0.44		鮎48g
	タマゴ(加工品)	50g			1.25					1.25		伊達巻き40g
	すり身	18g			0.30					0.30		サツマアゲ60g
	煮野菜	5g			0.25					0.25		煮野菜20g
	タケノコ	11g										
	大根											
	にんじん											
	なす											
	切り干し大根											
	シシトウ	5g										
	その他の野菜	28g						0.46		0.46		茹でた野菜210g
	油	9g					1.00			1.00		9g
	砂糖	7g							0.35	0.35		1g 4kcal 20g
調味料											少々	
合計			3.40		2.47		1.00	0.46	0.35	7.68	614.09	

香取弁当: 総カロリー 614.09kcal

塩分 約5g

FIGURE 6-2 The Calorie Counting Chart (*karorī keisan hyō*)  
(Courtesy of members of the *Kuromatsu-no-kai*)

After they looked up ingredients one by one in the official *Food Exchange List*, they entered them into the pre-structured tables on their home-made Calorie Counting Charts—next to the weight—that mapped the items of the lunch-box against their nutritional values. Each item of food on this list were grouped into six categories (starches, meat, vegetables, etc.), following the official list, and their energy intake was converted into a common denominator of 80kcal (1 unit) making it easier for patients to substitute one type of food to the other and compare it to the recommended daily food intakes of each individual. For example:

$$\begin{array}{rclcl}
 \text{minced fish} & & \text{Group 3} & & \\
 (\text{kamaboko}) & = & \text{protein} & = & 1/6 \text{ of Sasakawa-san's daily} \\
 (18\text{g}) & & (0.3 \text{ unit}) & & \text{protein consumption}
 \end{array}$$

Calculating, classifying and converting the content of the three different *bentō* in this way, radish and *tofu* put on the character of nutrition even for those members who never in their life prepared a meal themselves and were mostly ignorant of the content of *bentō*. The following day, the final version of this home-made list was printed and handed out along with the lunch-box to all members of the *hanami* outing.

Following Foucault this could be described as a dispositif<sup>163</sup> of nutrition that allowed members of the *Kuromatsu-no-kai* to compare the three lunch boxes along some meaningful dimension: (1) tasty, but calorie-laden; (2) low calorie, but expensive; (3) a good balance between the two. The whole idea of calculating and comparing the contents of three different kinds of *bentō* was about choosing the most adequate one for the *hanami*, to begin with. Eating tasty food is a pleasure, but their calorie density is a source of stress. Low-

calorie *bentō* may be a solution, if you don't have to worry about your wallet. "Good balance" meant then, for the members of the patient group, a commensuration between calories and prices that align the multiple sources of distress.<sup>164</sup> But how?

At first, participants agreed that the third *bentō* box with its "good balance" was the best option if they decided to buy the same *bentō* for everyone. However, at this point, Suzuki-san cautioned the group that for some members even this amount of food was too much, so they might go for the one with the lowest calorie. To counter this argument, Shimazaki-san, an energetic woman in her early seventies, answered: "Well, it may require some endurance from those whose recommendation is lower (*dakara, gaman sureba ii deshō*). I hate to tell this, but couldn't they just leave the extra food in the box?" But Suzuki-san was far from convinced: "We go all the way to *hanami* and then we end up fuss[ing about calories]!" (*Sekkaku no hanami na no ni, ki wo tsukatte bakari*), she muttered.

The point is neither that patients have necessarily left this meeting with a nuanced understanding of nutritional values; nor that these activities had a profound effect on their daily management of diabetes (although it might had for some). What I suggest, rather, is that in the technosocial commensuration of numbers, types of nutrients and the daily pleasure or anxiety of eating, personal and social distress of diabetes were fused into each other in a new—metabolic—collective. We could say that, here, it is the scientific that incorporates the collective into the personal experience of disease. As Bruno Latour put it in another context: " (...) we don't assemble because we agree, look alike, feel good, are socially compatible, wish to fuse together, but because we are brought by divisive matters of concern into some neutral, isolated place in order to come to some sort of provisional makeshift

(dis)agreement" (Latour 2005b: 21).

The next day, I went to the *hanami*, which, thanks to the fine weather, was attended by almost all active members of the group making it a successful learning experience (see *Figure 6-3*).<sup>165</sup> Before dispensing the lunch boxes, Shimazaki-san took the lead by explaining the pros and cons of leaving some food in the box:

*Shimazaki-san: Dear friends, please check the Calorie Counting Chart we prepared yesterday for you. You will find all the ingredients of the bentō and the energy content of it in [food exchange] units. I'm sure that it will be too much for some of you, so please check your daily calorie prescriptions before you start to eat and adjust the content of your lunch to it. It's okay to leave food in your box, so start with your favorite ones. I admit that it's not easy, but think of it as some kind of "stress relief game".*

As his preamble indicates, food provoked intense concern and worry as it was converted into nutrition because, and insofar as, stress and diabetes extended into each other due to the collective calculation of caloric intake.

Distress may not be the direct cause of high sugar levels (biologically speaking, it's actually the other way around), but local understandings of what actually can be sensed as stress, and how, may follow the daily practices of diabetes management. In the quest to articulate a collective identity of disease, the fact of being different happens to be a very stressful experience. But how did the invocation of endurance (*gaman*) at the site of preparing lunch boxes bring individuals together by translating bodily experience into culturally recognizable forms? This question leads me to the consideration of the relation between stress and disease, a classic debate in medical anthropology.





**FIGURE 6-3** Assembling disease: calories, patients, cherry blossom  
 Nutrition training at Murata-san's home (above) and *hanami* in Kinshichō Park (below) with members of the *Kuromatsu-no-kai*, April 2006. (Photo by the author)

#### 4. The stress of chronic disease

The collective engagement with chronic disease that I described in the previous case study elucidates as much about the limits of the comparative method as about its indispensability in anthropology. That the all too common stresses and irritations of modern life are both a ubiquitous part of the human condition and a factor of disease is already common knowledge. There has been much discussion of how the stressful events of modernization, for example associated with social inequalities, urbanization and migration influence the incidence of diseases such as rheumatism or asthma (see e.g. Kopnina 2016; Manderson and Rose 2000; Pugh 2003). This literature is replete with epidemiological studies<sup>166</sup> in which stress is embedded in the social and historical context of different populations on the one side, and psychology-minded approaches that frame their concern in terms of subjective experience on the other.<sup>167</sup>

Medical anthropologist William Dressler, for instance, argues that the symmetry between stress and chronicity is of a social kind. He coined the concept of *lifestyle incongruity* to capture how social inequalities become persistent in chronic disease. He investigated the incidence of high blood pressure in both developing (Brazil) and wealthy (United States) countries finding that the inconsistency between one's actual socioeconomic status and his desired material lifestyle correlated with the incidence of high blood pressure. Lifestyle incongruity, in this formulation, is thus a chronically stressful condition associated with conditions like high-blood pressure and diabetes.

This notion of inequality makes a clear claim that stress is a feature of modern, hierarchical societies. Meanwhile, other studies show how it may be attenuated by social support systems of family or community groups

(Dressler et al. 2005). When faced with the growing prevalence of diabetes worldwide, epidemiologists fasten upon such notions of cultural change and Westernization, and the anxieties of modernization serve as an unproblematic pathway from social inequalities to the epidemics of diabetes. As we have seen in Chapter 5, epidemiology all too easily slides into genetic explanations and the focus on cultural change and distress provides a way to bypass, if not actually to confront, such ideas. Yet, for others, it is the very context of this modernization in which thrifty genes and cultural differences explain each other (e.g. Diamond 2003; Zimmet 2000). Dressler and his colleagues, however, try not go along the modernization paradigm but turn it on its head. They use a cognitive approach to suggest that it is a specific cultural knowledge "distributed across individual minds" that enables members of society to balance their realities and desires. The lack, or low level of such 'cultural consonance,' they argue, is a stressful experience, which enhances the risk of chronic disease (Dressler and Bindon 2000).

Others claim that stress and disease complement each other not in a social, but in a cultural way. In their effort to link collective trauma and high blood sugar, the authors of the anthology *Indigenous Peoples and Diabetes* take a historical approach and consider the interplay of acute and psychological stress factors in the high prevalence of diabetes mellitus among the first peoples of the Americas and supposedly other colonized populations of the world (Ferreira and Lang 2006). "Stress," they write "is a trigger for hyperglycemia and the development of adult onset diabetes. (...) The hypersecretion of stress hormones called glucocorticoids are antagonists to the production of insulin. (...) Emotional, psychological and spiritual stressors combine with nutrition trauma to contribute to the dramatic breakdown of indigenous societies—manifestations of neocolonial induced cultural and

historical trauma (Korn and Ryser 2006: 252)."

The locus of critique here is the prevailing genetic model of diabetes and the failure of public health interventions that have aimed to change lifestyles in the name of fighting against the global epidemic of diabetes. The message implied is that the solution forms part of the problem. Public health experts happen to represent the same Western reason that served as the *modus operandi* of placing native people at risk for diabetes through the *cultural trauma* of colonization. What if, they propose, applied anthropologists put their outdated notions of cultural norms and behaviors on the shelf and adopt a more practical approach whose prototype is knowledge (Ferreira and Lang 2006: 17)? If cognitive and emotional aspects of disease are taken more seriously, they argue, anthropologists may be able to help native people to design their own methods and narratives for dealing with diabetes. Support groups, talking circles, oral history workshops and other related activities, for example, might all be important components in the prevention and treatment of diabetes by relieving the distress of genocide and social suffering (McGrady and Grower-Dowling 2006: 389).

Both images, that of society and that of culture, are inherent in the idea that there is a common denominator that translates stress into disease and vice versa. This returns us to the problem of comparison that was left off at the end of the previous section with the debate over the ingredients of *bentō* at the *Kuromatsu-no-kai* meeting. The notion of commensuration may be useful for underscoring the limitations of the vast array of scholarly work on the relationship between chronic disease and stress.

## 5. Eating together 2: school lunch

The following case aims to illustrate the profound significance of such work of commensuration between biomedical categories and the multiplicity of suffering. It concerns school lunch and herbal tea and the way they figure in the logic of the metabolism. Of particular interest in this story is that its main character is in a situation similar to that of the members of the *Kuromatsu-no-kai*, but the collective he relies on is of a far more hybrid kind (Bungeishunju 『文藝春秋』 2009).

**血糖値を気にせず  
飲食できるということ。**

高血糖を克服するには食事制限と適度な運動を習慣づけることが大切。とはいえ、それは思以上に難しいことでもある。なかなか成果が上がらないことから、過度なストレスがかかり、状態をさらに悪くさせる人もいるというからやっかいだ。ここではそんな悪循環を断ち切るのってきた、ある人物の話を紹介しよう。

**加齢による代謝の低下  
そしてストレス……**

石川県で教職に就く大森俊彦さん（60歳）が高血糖を指摘されたのは今から5年ほど前。近親に糖尿を患う人もおらず、当初は不思議に思ったというが、加齢に伴い代謝機能が弱まるのは無理もないことだと改めて実感したの

とるんですね。でも、給食というのは生徒たちに合わせて作られていますから、高血糖の私にはカロリーが高すぎるんです。という立場上残せませんしね。それでなんとか昼食以外の他のところでカバーするよう努力していたんですが……

大森さんは朝食と晩食を控えることでカロリー摂取量を抑えていたの

「本来、お通って楽しく飲むものですが、と語る大森俊彦さん（60才）。血糖値を気にせず飲めるお通は格別とのこと

「驚くほど良くなったんです。今、血糖値はまったく問題ありません。カロリーを気にせず食事できて、好きなお酒も楽しく飲めるんですから本当に有難いことです。ストレスも不思議なくらい無くなりましたね。コレステロールも体脂肪も問題なくなりました。先生にもこのお茶のことを言っておつね。すると『薬で無理やり若い体に矯正してしまうより、このように天然のもので自然に血糖値の上がりにくい体をつくるほうがいい』って賛成してくれて（笑）。このお茶には本当に感謝していますよ」

**好きなものは楽しく味わいたい**

そんな時、大森さんは高血糖に良いといわれる健康茶を見つけたことになる。そして半信半疑ながら飲み始めたのだと、すると予想以上の好結果がもたらされたというのだ。

「驚くほど良くなったんです。今、血糖値はまったく問題ありません。カロリーを気にせず食事できて、好きなお酒も楽しく飲めるんですから本当に有難いことです。ストレスも不思議なくらい無くなりましたね。コレステロールも体脂肪も問題なくなりました。先生にもこのお茶のことを言っておつね。すると『薬で無理やり若い体に矯正してしまうより、このように天然のもので自然に血糖値の上がりにくい体をつくるほうがいい』って賛成してくれて（笑）。このお茶には本当に感謝していますよ」

あれほど血糖値で悩んでいたのが今では不思議に思えるのだと大森さんは嬉しそうに振り返る。

では大森さんが欠かさず飲んでいるお茶とはどのようなものか。それはギムネマ、グアバ、バナバ、桑といった糖に働く7種類の植物を原料とした「干濃茶」。お湯やお水にサッと溶ける顆粒状で、いつでもどこでも簡単に飲用できるという手間要らず。血糖値にお悩みの方は、一度試してみればいかがだろう。価格は1箱に約1ヵ月分、10,500円（税込）、まとめて3箱だと10%引（その場合は代引にて）。詳しくは左記の販売元まで。

電話 0120・788・8202  
FAX 03・5251・1778  
お通はつづ堂「中央公論」係

干濃茶

血糖値を気にせず  
飲食できるということ。

（PR）

FIGURE 6-4 *Senrin-cha* [Advertisement]

Source: *Bungei Shunju*, December 2009

Ōmori Toshihiko is a teacher in his early sixties who has had diabetes for five years. He lives in Ishikawa prefecture on the Japan Sea coast, in the west of Japan. Although he tried hard to take good care of the food he eats, his blood glucose is far from being well controlled. One reason, he suggests, is the school lunch: "In the school, children and teachers eat lunch together, as you know. But the school lunch is prepared for children of growing age to fuel their physical development. For someone like me with high glucose levels it is way too much calorie. But as an educator, I'm not in a position of leaving the food on the plate. So, eventually, I have to find other ways to make up for those extra calories" (ibid; translated by the author).<sup>168</sup>

Despite all his efforts, at the monthly visits in the clinic, he is confronted with test results that are anything but encouraging: "Hardly any improvement...I was knocked out. What's all that sacrifice for? That's how I felt" (ibid; translated by the author),<sup>169</sup> he recalls with a bitter smile. Such stories of endurance and determination are clichés that circulate in TV talk shows, appear on the pages of tabloid magazines and are especially popular among diabetes patients and their families in Japan. It is a narrative frame of vicious circles of coping with disease in which the gaps between diagnoses and the patient's own sensations is recognized as the source of distress and the very cause of increasing glucose levels. All this is of great importance for the anthropologist, who, compelled to question social and material conditions of disease, may quickly add that such distress also fundamentally informs, and is informed by social institutions, like the school, and material conditions, like food in the daily management of chronic conditions.

But Ōmori-san's story of treatment fortunately doesn't end here. For in fact his story is one of those tabloid tales from the advertisement of a health food distributor taking up the familiar narrative to confront it with the happy

ending it tends toward through their tea named *Senrin-cha* (Figure 6–4). Many so-called health teas are marketed in the therapeutic context of diabetes as possible hypoglycemic agents, and though most physicians recommend traditional Japanese diet to their patients, health products are viewed with considerable suspicion. It is no surprise therefore that Ōmori-san encounters *Senrin-cha* not in a hospital, but through the recommendation by a friend. At first, he is suspicious (like his physician), but nevertheless he gives it a try, and soon gets more than he expected: "It was amazingly effective. I have no more problems with my glucose levels (...) And what is more, all the stress has curiously disappeared. No more problems with cholesterol levels and body fat," he concludes (*ibid*; translated by the author).<sup>170</sup>

The stakes in aligning different dimensions of disease is well illustrated in this advertisement. The school and the hospital, eating and measuring, glucose levels and stress, all these entities are bound up with each other in a process of commensuration facilitated by the marketing of the tea as an over-the-counter, mass produced solution to social responsibilities and weak bodies. Practices of commensuration linking consumers, citizens, food and disease in the marketing of *Senrin-cha* and other health products organizes reciprocal relations between metabolic conditions and distress.

What does such configuration say about the work of comparison in medicine and healthcare?

## **6. Commensurating disease**

As part of the comparative tradition in the discipline at large, anthropologists have produced a large body of knowledge about the incommensurable worlds of disease. It has been described as the product of plural medical traditions from Ayurveda to biomedicine or conceptualized in terms of

embodied difference (Das 2015; Leslie and Young 1992). Yet, while claims of medical pluralism and particularistic accounts of social suffering have both contributed to shaping the field of medical anthropology, there are still very few works in the narrower discipline that have carefully considered how such radically different knowledges and experiences hang together in practice.

From a methodological point of view, the *a priori* dependence on interpretive frameworks of comparison in ethnographic fieldwork bypasses some important links that medical practice creates between the apparently incommensurable realms of doctors and patients, or biology and suffering, or diabetes and stress. For better or worse, phenomenological and cognitive traditions tend to divert in our ethnographies (Tanabe 2008: 58). But to a closer look, such divergence is not at all trivial.

The anthropologist's strategies of aligning her interest in human experiences and cosmologies with medical practices of prevention and treatment cut across those of the epidemiologist who ventures into the anthropological realm on her way to understand the quantifiable aspects of human difference. People desire better lives both in Brazilian slums and African-American communities in the rural South of the United States, and such social inequalities generate higher blood pressure in both places. Indigenous populations from the Yurok Indians of California to aborigines in Australia have been struggling with a traumatic past, which may be historically different, but nevertheless lead to the same pathological condition of elevated blood sugar. The two distant worlds, which medical anthropologists used to call disease and illness, include each other in multiple ways that are nonetheless fundamental, although less easy to account for in the language of anthropological comparison. But then the comparative method is by no means a prerogative of anthropological thinking. Genetic



epidemiology, for instance, took upon itself no less than the challenge of identifying the underlying causes of different incidents of disease in different populations with shared genetic heritage, diverse patterns of lifestyle, and complex environmental impacts (Franco 1996; Rice et al. 2006; Stevens et al. 2013). Thanks not least to the increasing number and comparative technologies of transnational clinical trials, socially significant categories—such as group identities and gender differences—have become ubiquitous in medical research in recent years adding to the general sentiment that health is a *political* problem.

If we take what Nikolas Rose calls 'vital politics' (Rose and Novas 2005) for granted, such changes have been made possible by rapid developments in the life sciences and neoliberal forms of governance. Along similar lines, a series of recent ethnographic studies have documented how grassroots activism and patient advocacy entered into—and, at the same time expanded—this political space to question taken-for-granted categories of comparison and the future of disease by insisting on the heterogeneity of patienthood (Fullwiley 2011; Ushiyama 2015). Yet it would be a mistake to stop the analysis here. After all, the politics of disease, as Foucault has long demonstrated, is more complex than can be captured with the dichotomy of hegemonic modes of truth-making versus resistance.

As the editors of a special issue titled "Evidence-based activism" in the journal *BioSocieties* noted, "[f]rom a conceptual standpoint, 'evidence-based activism' sheds light on the on-going co-production of matters of fact and matters of concern in contemporary technological democracies" (Rabeharisoa et al. 2014: 111). This approach is, indeed, compelling, and can be taken a step further to the question which is most relevant to the theme of this chapter, commensuration: how simple and complex might relate in ways that do not

turn them into interrelated opposites (incommensurable worlds), dualisms related by difference, that is *not plural*.

Both activists and social scientists like to emphasize the difference between difference and deviance. Its recognition by the medical sciences might help you to get healthier if it brings better and more appropriate healthcare and prevention by political means. But does it really? It's not easy. People living with diabetes have many stories to tell about hiding in the corner at a party far away from the table where all the other people gather through the social act of sharing and consuming food, and the like. Being different is a lonely state, especially when you are sick. For biomedical variations are not mere categories, but forms and norms of daily life that one has to learn to live with.

Although high blood sugar levels and stress are classified as two different conditions in most of the endocrinological literature, in the daily practices of coping with disease they are rarely enacted as distinct forms of suffering. Physicians and nurses expect self-control to be stressful, and its expression is often encouraged as a form of improving the treatment of disease. As we have seen in Part I, such modes of care are embedded in the long process of learning to live with chronic illness, and there are no evident divisions between them as, for example, in the case of different categories of complications. In the logic of care the continuity between disease and stress is a practical element of the clinical enactment of diabetes and therefore the act of *comparing* one patient's social suffering with another is rarely accounted for in explicit ways.

Such permeability between incommensurate worlds is indeed a vital element of contemporary healthcare both in clinical settings and beyond (Rock 2005c). The way metabolism, a model *of* the transformations of food

inside one's body, turned into a model *for* patient advocacy suggests a novel articulation of what it is to have a (metabolic) body in contemporary Japan. The activities of the *Kuromatsu-no-kai* suggest that patients' advocacy can articulate new modes of comparison that tolerate the divergence of distinct entities. As we have seen, disease and stress emerge (again) as separate entities when unique experiences clash with one another and singularities are shared at the meetings of the self-help group. It is through this never-ending battle of glucose control that individual trajectories of distress—from strict diet therapies to the anxiety of complications—open up a new field of knowledge about diabetes. Considered in this way, anthropological inquiry can be depicted as a theoretical device that promises to reveal the implicit links between multiple levels of suffering. Commensuration, we may say, is a form of anthropology as well as its content, both an explanatory resource and an achievement to be explained.

## CHAPTER SEVEN

### **Metabolic Togetherness**

*in which things are drawn together and the ethnography of disease reveals its theory*

Chronic diseases, *in practice*, have no conclusions. You have to continue *living with* it until they become, well, the conditions for life. As I have argued throughout this thesis, for people living with diabetes, such life is an effect of their metabolism. The implication of such an ethnographic foregrounding of metabolic worlds is twofold. On the one hand, it allowed me to follow the porosity between bodies and environments that, in turn, have the potentiality to open up the rigid divisions between individual experiences and expert knowledges, natures and cultures, technological and social worlds. At the same time, the analytics of the metabolism promises more nuanced insights into the cultural, social and political work that these passages between organisms and environments make possible (Solomon 2016: 227).

By exploring the manifold interconnections of living with and keeping track of high levels of sugar in the blood, I hope to have provided a degree of insight into the increasingly prevalent experience and profound politics of chronicity in contemporary Japan.<sup>171</sup> Self-initiated therapies of chronic conditions require technologies that are designed to make space for a multitude of negotiation, tinkering, experimenting and self-objectification (Fukushima 2001: 96–98). I have argued throughout the thesis that these conditions situate people in a complex set of relations of technologies, markets and ethics that are multiply determined and very open at the same time. Such relatedness is achieved, as I tried to show, by means of symbolic,

political and scientific artifacts-in-the-making (Biehl 2005: 118). As the crystallization of public health concerns around emerging lifestyle diseases (*seikatsu shūkanbyō*) shows, the subtle shift toward more active involvement of chronic patients in their lifelong treatment is deeply intertwined with the political potentials of mundane devices.

The first half of this thesis, Part I, dealt with the emergence of mindful metabolic bodies by looking at the local sites of diabetes care where high glucose levels are embodied in an ongoing process of *learning disease*. Here, I was concerned to illustrate how diabetic bodies are 'becoming with' medical technologies at the metabolic juncture between sensing selves, biological values and the micropolitical (re-)configuration of 'normal' ways of living with disease. In Part II, I approached *diabetes as a comparative entanglement* between state-of-the-art science and public health intervention on a massive scale. Different facts and experiences structure the knowledge about diabetes that emerges from the interferences of particular scientific and cultural attributes. Some repertoires invoke "Japanese genes," whereas others inscribe a stereotypical male diabetes patient, the *sarariman*, or company employee.

The puzzle is this: how do these different subjects of clinical medicine, molecular biology and epidemiology come to stand for the same disease? Or, do they at all? The argument presented in this thesis contends that such interaction is made possible through the constant work of the metabolism.

In this final chapter, I return to the question set out in the Introduction: how do biomedical technologies and innovations force us to rethink the fundamental anthropological problem of difference? After drawing together and building on the main themes explored in this thesis, I will propose the notion of *metabolic togetherness* as a mode to extend the ethnographic method beyond the notion of pluralism and diversity.

## 1. Learning and comparing

In the past twenty years, anthropology alongside other human sciences, at last seems to have opened up its once rigid theoretical frameworks and methodological toolkits to embrace the concept of life—not as something that divides social and natural phenomena, but rather as a heuristic device that highlights how they relate to and include each other in practices, not least medical ones (e.g. Kaufman and Morgan 2005; Kohn 2007; Pitrou 2017; Tanabe 2010). Crucially, this relatively new concept of life has emerged out of research that followed the movement of living objects: genetic materials going between laboratories and regulatory agencies, mushrooms traveling between distant mountains and global markets, and organs switched between living bodies, to mention just a few examples (Choy et al. 2009; Rabinow 1999; Yamazaki 2015). As Peter Keating and Alberto Cambrosio suggested in their sociology of biomedical platforms, such mobility is an important element of the politics of life in contemporary biomedicine:

Regardless of the plan or project, (...) there is a problem common to any attempt to articulate biology and medicine: both are moving targets. Priorities in medicine respond to changing patterns of public health. (...) Similarly, priorities in biology change and today's research frontier may be tomorrow's relatively mundane undertaking. The latter problem is particularly acute. While some diseases such as cancer can safely be assumed to remain priorities over the long run, it is often impossible to predict what fields and techniques in the fast-moving world of biology will ultimately prove significant for the study of a particular disease or class of diseases. Decisions about the future, nonetheless, have to be made and the interim attitude has generally been that something will turn up. (Keating and Cambrosio 2003: 78)

This thesis explored the consequences of such mobility by drawing on current

ideas in, and across, science and technology studies (STS), medical and cultural anthropology and Japanese studies with a view to carving out *an ethnographic theory of disease*.

Through an ethnographic engagement with various technosocial situations of diabetes care in Japan, I followed two ways in which the metabolism is acted upon: learning and comparing. How does the body of the diabetic patient—from (thrifty) genes to fat bellies—become an experimental site of technological and social innovation in contemporary Japan? What is at stake when diabetic bodies move across different locations and scales in comparative practices of epidemiology and genetic research? These are among the questions I pursued at the sites of diabetes research and treatment throughout this thesis. Together, the six case studies presented above have indicated a constant fluidity between different values (e.g., numerical, familial, ethnic, aesthetic, genetic, etc.) and different ways of ordering reality (e.g., political, clinical, technological, embodied, etc.) of metabolic disorder.

\*

Among the key elements in understanding the metabolism as an increasingly important passage between human and nonhuman worlds I addressed in Part I is the appropriation of simple medical technologies by patients and the multiple frames of differentiation that emerge from the clash of technological manipulations of and on the human body. This, I have shown, unfolds in an open-ended process of learning: *emplacing*, *encountering* and *embodying* metabolic differences.

Recall, for example, the diagnostic device of fluorescein angiography in Chapter 2. By making diabetes and its complications visible for patients

without much previous knowledge and interest in their condition, this primarily diagnostic device designed to detect complications in one's eyes serves as a very effective instrument of learning. "*Here, here, can you see that this part of your eye is slightly different from the rest? Here, the vessels are swollen. You can't feel it, but it may burst.*" The relatively simple act of literally *looking* into one's own retina let people discover hidden damages and hitherto unknown bodily signs. At the clinic, patients learn to *encounter* their metabolic disorders.

The self-measuring of blood sugar levels that I discussed in Chapter 3 offers another way for people to engage with their own impaired bodies. Patients are trained not simply to develop the skills of measurement, but also to activate their senses and to embody disease again and again. In collective training sessions of blood sugar measurement, patients learn to compare formerly neglected reactions to high and low glucose levels. Moreover, they record these changes in a tiny notebook in order to interpret them on their own, as the records accumulate, or to show doctors qualified to explain their medical meanings.

The shared practice of using mundane tools, anthropologists argue, connect people, forms of knowing, and identities. Acquiring the skills and tools necessary to monitor chronic conditions, according to this argument, is a series of mediations between medical experts, patients and their families; between radiology labs and the nurse station; between discovering metabolic disorder and treating it; between the stigma of sickness and the organization of self-help groups. Chronicity, in this sense, becomes a mode of *embodying* difference.

In their seminal work on situated learning, Jean Lave and Etienne Wenger claimed as follows: "Understanding the technology of practice is more



than learning to use tools; it is a way to connect with the history of the practice and to participate more directly in its cultural life" (Lave and Wenger 1991: 101). In this argument, the act of learning emerges as a process leading to increasing participation in communities of practice, something that psychologically oriented theories of learning had previously ignored. The connectedness of cultural life, or so Lave and Wenger suggest, depends on certain artifacts and their taken-for-granted logic, to the effect that tools and instruments generate specific activities around which particular communities take shape.<sup>172</sup> This "cultural organization of access" is constituted by what they call the *transparency* of technologies' mediating" function. "It combines the two characteristics of invisibility and visibility: *invisibility* in the form of unproblematic interpretation and integration into activity, and *visibility* in the form of extended access to information" (ibid: 103). Devices are often too complicated and most of us lack the technical knowledge of their internal workings. In daily routines, they are left uninspected and more often than not the specific purpose of their use remains unquestioned.

Where a more orthodox anthropological focus is on participation in communities, an image of homogeneity and stability of technologies emerge. But what if learning creates as many questions as it answers? What if the information gathered through a multitude of artifacts do not add up to a coherent whole? What if technologies are acted upon in their complexity not to disguise but, on the contrary, to *make differences*? Given the place of diagnosis in the general configuration of medical practice, such questions highlight the productivity of artifacts in the ongoing self-care of chronic illnesses. It further opens up to an understanding of biomedicine not as reduction but as disclosure of the multiplicity of human experiences.

Throughout this thesis, I have described differences as vital elements in

coordinating the outcomes of medicine. As elucidated in the first part, learning to live with medical technologies (1) provides means for the attunement to bodily differences on the one hand, and (2) links up to sensitive and "interested" bodies in a variety of collective identities on the other. That is to say, the appropriation of *diagnostic and other technologies* cut across socio-cultural patterns of *bodily techniques* while making use of and performing them. The more technologies, the more mediation. The more mediation, the more difference. Human and non-human entities form irreducible links in this chain of shaping and appropriating variations (Latour 1988).

\*

In Part II, the focus shifted from the hospital to other sites of diabetes research and treatment, as I followed the movement of metabolic disorder between laboratories, clinics, administrative and regulatory agencies, and patients' homes. In tracing these metabolic mobilities and their enactments in endocrinology, epidemiology, molecular biology and public health, a complex world opened up in which questions of difference and similarity were settled in practice. At the same time, this suggested an alternative way for anthropologists to examine heterogeneity—on the move. In these moves life becomes a target of, and ground for, comparison. As we have seen, metabolic lives and life forms are constantly compared in the world of diabetes care and prevention: *included* into the design of clinical trials, *interfere* in genetic research and *commensurated* in patient activism. This heterogeneity call for further research that explores the relation between comparative practices and the traveling objects of medicine and the life sciences in general.

Since its inception, much of the anthropological agenda has been

revolving around various forms of comparison. Take the following definition of anthropology from the introduction of a contemporary textbook: "Once anthropologists realized that racial biology could not be used to explain why everyone in the world did not dress the same, speak the same language, pray to the same god, or eat insects for dinner, they knew that something else must be responsible for these differences. They suggested that this 'something else' was culture" (Schultz and Lavenda 2004: 9). And while arguably most anthropologists in the 21st century look for alternative analytic grounds for difference, comparison continues to constitute the epistemological backbone of our discipline (Gingrich and Fox 2002; Goody 1969; Holý 1987). Whether viewed as a 'method' (the comparative method) or as an 'attitude' (reflexivity), comparison turns out to be, to paraphrase Marilyn Strathern, a "heterogeneous spectrum of middle-range strategies, mainstream and subaltern, that sustained the discipline along numerous lifelines" (Strathern 2002: xiii).

Such connections are often reduced to the level of physical and material reality on the one hand, or explained away as metaphors or numbers on the other. To avoid both kinds of determinism, I proposed to look at the constitutive role of comparison in three different experimental contexts. In Chapter 4, I discussed the ways clinical trials are designed to *include* more and more social differences into the epidemiological comparison of metabolic disorder. Chapter 5 followed genetic research of the so-called adiponectin hormone. I argued that these knowledge practices make newly discovered drugs *interfere* with epidemiological concerns by comparing ethnic, gender, and pathological variations. As a result, methodological questions become political acts. In Chapter 6, the mundane comparative practices of diabetes patients around food and eating helped me to account for the work of

*commensuration* between different modes of living with diabetes: as metabolic disorder and as psychosocial distress.

The argument presented in Part II aims to contribute to discussions around the increasingly fluid relationships between biological and social realms—or, in a different context, experiment and care—in the 21st century, and about the politics of life both as a cause and an effect of such fluidity (Epstein 2007; Fukushima 2005c; Keating and Cambrosio 2003; 2011; Thompson 2005). On the one hand, as some observers have pointed out, the growing need for comparing medications and therapies might generate better conditions for treatment, folding experiment and care into each other in new ways (Mol 2002b; Timmermans 2010). As a consequence of such transitive relationships, care practices transform the very notion and method of comparison: patients now are partially connected with their medications, health professionals, and other patients, in a world-making project of difference, forcing the anthropologist to reconsider her own method of comparison (Mohácsi and Morita 2013; Niewöhner and Scheffer 2010).<sup>173</sup>

My fieldwork in research facilities and treatment settings in Tokyo and Hokkaido suggests that much of the tension between treatment and prevention of diabetes derives from a limited idea of what a good comparison is. When one compares two objects, according to this narrow concept, their relations are defined in advance, on a fixed scale. This may work for epidemiological research, when, for example, one compares disease entities with other disease entities or drugs with other drugs, but is not quite so straightforward in medical care, where bodies and drugs inhabit each other's worlds in both ontological and metabolic senses (Hattori In press; Mohácsi 2017). The metabolic pathways that connect these worlds are neither merely symbolic nor radically material. By bearing the potentiality of inventing

relations between incommensurable levels of difference, they turn into comparative facts of embodied relations.

## 2. Another politics of life: living together with the metabolism

*By 'the political', I refer to the ontological dimension of antagonism, and by 'politics' I mean the ensemble of practices and institutions whose aim is to organize human coexistence.*

—Chantal Mouffe

When asked about the unique feature of diabetes, both experts and patients will be quick to point out that despite all the technological innovations and pharmaceutical discoveries of the past two decades, the management of eating (and, to a somewhat lesser extent, exercising) remains the cornerstone of both treatment and prevention. Life with high blood sugar levels, in other words, is a matter of *learning to live with our (and others) metabolism*. But how? This is a question that emerges time and again in both explicit and implicit forms in the daily practices of care at the clinic and scientific research.

The links between a common sense of knowing disease and the experience of coping with chronic conditions in the term *byōki to tsukiau* is noteworthy here, because it suggests the relations between disease and life on the semantic level. The word *tsukiau* is a fairly common verb in Japanese language used to describe a form of association or relation where the two sides provide company to each other. Therefore, one of the most common English translation is "to accompany" or "to associate with." In certain cases, it may be used to describe romantic relations, such as "to date" with someone. In chronic disease, however, by adding *byō(ki)* (disease) in front of the word *tsukiau*, denotes the lifelong relation of living with a certain condition, for

example, high levels of blood sugar (*tōnyō-byō to tsukiau*).

The metabolism "reminds us that as substances bleed between the body and the world, they effect changes upon how both domains interrelate," anthropologist Harris Solomon observed in his monograph on 'metabolic living' in Mumbai (Solomon 2016: 229). As the term *byōki to tsukiau* suggests, such anthropological claims feed quite easily into ethnographic theories in the practices of living with diabetes in Japan. In this sense, the metabolism is meant to empirically articulate what others in different contexts have been discussing in terms of togetherness and worlding (Bertoni 2016; Zhan 2009). Medical technologies and bodies become enmeshed in each other through care, experiment, learning and comparison in a way that I would term the "worlding of the metabolism." Following anthropologist Mei Zhan, I contend that the metabolic body "needs to be 'worlded'—made visible and thinkable rather than concealed and 'banished to the earth'—through cultural analysis and as cultural analysis" (Zhan 2011: 109). Thus, I use metabolic circuits here as a metaphor *not of* our interconnected world *but rather through* the conduct of an ethnographic experiment.

The metabolism offers an intriguing possibility for shifting how we can think about the co-existence of multiple worlds, the relationship between subjects and objects and the entanglements of technological and cultural differences in anthropology. Eating is probably as close as one can get to the mutual inclusion of natures and cultures. Even a popular textbook definition will admit that much, if somewhat concealed: "The basic principle underlying our energy metabolism is simple. Nature requires energy to ripen an apple on the tree. We humans come along and break the apple down into its constituent molecules and metabolize them for energy" (Enders 2015: 42).

The term metabolism was established in the 19th century at the

crossroads of organic chemistry and experimental physiology of plants and animals. It was soon taken up by political and social theorists to describe relations among people and their environment. The earliest and probably most famous usage was Marx's description of the dialectical interaction between nature and human society (Marx 1981 [1883]: 949).<sup>174</sup> Another, present-day example from science studies is Adrian Mackenzie's exploration of the Anthropocene body as a metabolic process (Mackenzie 2014). One of the most powerful metaphors of life, the metabolism gradually came to define the line—with all its permeability—between the living and the non-living. For example, between medical technologies and humans.

As we have seen in Chapters 3 and 6, diabetes patients try to control their sugar metabolism with the help of diagnostic devices and nutritional exchange lists. But this is not at all an easy thing to do. First of all, as Annemarie Mol and John Law suggest, they need to develop a sense of their own metabolism.

One of the crucial steps in acquiring self-awareness is the ability to differentiate between self and other, between who one is from the inside and what, because it is outside, one is not. However, for the metabolic body, inside and outside are not so stable. Metabolism, after all, is about eating, drinking and breathing; about defecating, urinating and sweating. For a metabolic body incorporation and excorporation are essential. (Mol and Law 2004: 54)

This porosity is obviously a source of suffering for diabetes patients, but it is also a point of departure for exploring the politics of togetherness specific to eating. Both as a metaphor and as practice, metabolism directs attention towards usually unexamined ways in which subjects are not straightforwardly the authors of their actions: technologies, bodies and nature are all mutually shaped *and* reconfigured in the same process (Candea 2013).

This is one reason why the metabolism cannot be controlled. It offers no easy control either.

More recently, anthropologists and historians of science added important new insights by exploring how metabolic pathways perform their own collectives, divisions or even novel ways of writing (see e.g. Bonelli 2015; Landecker 2013; Solomon 2016, etc.). Importantly, these pathways reach beyond human differences and relations. In a truly experimental article on the interspecies and, indeed metabolic, relations involved in vermicomposting, Sebastian Abrahamsson and Filippo Bertoni put forward the following notion of togetherness: "Feeding/eating," they say "with its transformative and relational character, allows us to conceptualize togetherness as a patchwork, as a composite of differences that do not necessarily require a common world" (2014: 144). We eat together, but we metabolize our food alone. But do we, really?

As Michel Serres (1982), demonstrated in one of the rare philosophical books that takes eating seriously, *eating* and *knowing each other* are much more intimately related than most of us would usually admit (Mol 2008a: 36. n.23). In *The Parasite*, the social event in which a host feeds guests while getting stories in return is a central element, reminding us of the inevitably metabolic nature of our heterogeneous ideas: being *is* relation. The focus on eating practices, in a strictly metabolic sense of the word, foregrounds this open-ended co-constitution of natures and cultures and the messiness of human and nonhuman togetherness. This has been, for long, implied by the work of Viveiros de Castro on perspectivism, but it is the renewed interest in the metabolism, inspired by the work of Annemarie Mol, Hannah Landecker and others, as an ontological crossroad between natures and cultures that could help to make the points of connection (along with, not contrary to their



radical alterities) between anthropology and STS more clearly articulated (Yates-Doerr 2017).

Amerindians, according to Eduardo Viveiros de Castro, inhabit a world where all kinds of relations are conceptualised in metabolic terms: "what one eats of man is always a relationship." Eating, in this world, is, also, an intellectual relation, an incorporation of different perspectives (Viveiros de Castro 1992 [1986]).<sup>175</sup> This particular kind of metabolic relatedness between predators and preys, we are told, creates eating and killing subjects who are also, and importantly, agents in their own eating and killing. Ingestion is thus at the heart of Amazonian sociality, where the act of eating is no less and no more than seeing the world, and the *body* of the eater is the seat of *perspective* on the world.<sup>176</sup>

This is quite different from Melanesia, according to Marilyn Strathern (2012), where eating is always put in relation to feeding. While ingestion, here too, is a central mode of articulating all kinds of social relations, it does not create subjects or perspectives in either the multinaturalist or the multiculturalist sense of these words. Rather than seeing the world, food, here, is the result of others' feeding. Or, as Strathern puts it in her inimitable style: "what one eats, of food or otherwise, is simultaneously the outcome of the agency of others" (ibid: 11). In the act of eating, Hageners *decompose* their social relations with others of which they are made.<sup>177</sup> Eating, here, points to the agency of people as they are implicated in the agency of others (Candea 2013). Rather than subjectivity or perspectivism, Strathern claims, eating points to how persons compose and decompose themselves, how they draw 'energy' from each other. Conceiving persons, in other words, is a kind of absorption and precipitation of each other's energy: a metabolic mode of living together.

'Living together' has also been an important focus of research and education at Osaka University during the past five years. By introducing the Japanese term *kyōsei* (共生) literally 'together'+ 'life'), researchers from various disciplines have been experimenting with new ways of thinking about the coexistence of different values, perspectives and knowledges in human societies (Atsumi and Inaba 2015; Kawamori 2016; Mohácsi and Imai 2016). The term *kyōsei*, however, has much more to offer in challenging the limits of EuroAmerican ways of doing politics. By virtue of its origin in the biological sciences (*kyōsei*=symbiosis), it is a tacit reminder of the entangled nature of contemporary politics with techno-scientific worlds. By engaging in the mundane practices of metabolic togetherness pushes us to highlight such entanglement all the more.

By focussing on the practical activities of living with a chronic condition, it is not too difficult to see that these points of connection are never stable: eating together, for example, is always, and at the same time, eating each other: something (someone) is folded into something (someone) else. In the case of living with diabetes, *the scientific knowledge of sugar folds the collective into the personal experience of disease*. The way the metabolism, a model of the transformations of food inside one's body, became a model for patient advocacy suggests a novel articulation of what it is to have a (metabolic) body in contemporary Japan.<sup>178</sup>

The question of who eats and what gets eaten in these metabolic and technological processes offers a ground for a more-than-human kind of togetherness: in chronic disease, and more specifically diabetes, we are neither kins, nor enemies, yet we are all each other's (metabolic) worlds.<sup>179</sup> As many of the studies around *kyōsei* suggest, this kind of togetherness is not about consensus, nor about a Latourian 'common world.' Contrary to categories

such as assemblage, actor-networks, collectives and commons, *kyōsei* attends to the mundane messiness of living together with incommensurable others: not only humans, but also disease, earthworms, or the planet.

### **3. Postplural anthropology as ethnographic theory**

Biomedical technologies have been instrumental in transforming chronic conditions from a linear decline of physical, cognitive and social abilities to a constant doing of togetherness. As renowned filmmaker and professor of Japanese studies at the University of Toronto Eric Cazdyn writes in his autobiographical critique, "the new chronic" is a state of "the already dead," a condition in which the subject has been killed, but has yet to die. What makes this condition possible for him is, among other things, a costly drug that helps to manage his leukemia for the rest of his life. "It performs a crucial ideological function" he adds, "that shapes the way we come to terms with everything from politics and culture to the most banal aspects of our everyday life" (Cazdyn 2012: 9). Medical technologies, including pharmaceuticals, are part of our bodies, our lives and—significantly for the argument of this conclusion—our theoretical repertoires, too. By supporting the management of chronic disease, self-care devices and pharmaceuticals, medical charts and experimental animals enable us to live and extend our lives. The more alive we are, the more our lives are embedded in these technologically managed worlds.

As I argued throughout this thesis, the metabolism has become a crucial "site" of such technosocial loops during the years that coincide with my ethnographic research. Thus, in a sense, I have built my theoretical toolkit from case studies of this interdependence that feed into the question of metabolic togetherness.<sup>180</sup>

My entry to the field site, as I described in Chapter 1, not only coincided, it also intersected with other emplacements of disease from the theoretical to the personal to the political. While I was familiar, for example, with ongoing theoretical debates around 'practice' (*jissen*) in Japanese anthropology, it was through my empirical encounter with similar discussions at the sites of diabetes care that shifted the main argument into a praxiographic direction. In a similar way, 'embodiment' (*mi ni tsukeru*) was not an intersubjective experience unique to the people struggling with illness—as I initially hoped (based on my readings in phenomenology and anthropology)—, but a clinical issue in patient education; 'inclusion' was a concern for the designers of clinical trials as much as an anthropological problem; and patients of the *Kuromatsu-no-kai* were just as much eager to find better ways of 'commensurating' nutrients and etiologies of their disease, as I was to compare their experiments with those of genetic research. In sum, diabetes was a theoretical concern, *because* of the manifold existential, organizational and political tensions it has sparked. More to the point, diagnostic technologies and pharmaceuticals played a crucial role in the mediation of these tensions and theories across lay and professional worlds.<sup>181</sup>

It was at these intersections that anthropological generalizations gave way to something that, after Giovanni da Col and David Graeber, I called ethnographic theory in the Introduction of this thesis: “ (...) a conversion of stranger-concepts that does not entail merely trying to establish a correspondence of meaning between two entities or the construction of heteronymous harmony between different worlds, but rather, the generation of a disjunctive homonymity, that destruction of any firm sense of place that can only be resolved by the imaginative formulation of novel world views (da Col and Graeber 2011: vii-viii). It was my initial concern with disease *and* its

ethnographic theorization together that led me to the idea of metabolic togetherness: arguably one of those "stranger-concepts"—along with *mana*, totem, and infrastructure—that may help us rethink the work of difference in the contemporary world and in anthropology.

There are, indeed, notable ancestors to build on. One may recall here Malinowski's theory of basic needs, where the "metabolism" imposes particular needs (eating, breathing, excreting) that have to be responded to culturally by "the community as a whole" (Malinowski 1944: 92). That is to say, for Malinowski and his fellow anthropologists. Since most of the Trobrianders have probably never heard about the metabolism, let alone cultural responses. Now, of course, this posed little problem when there were only anthropologists and missionaries visiting Melanesia and Western *perspectives* of the metabolism could be relatively easily separated from and compared to indigenous ones. But, in a world, where even in Melanesia, a healthier diet may help the mother of three to save her own leg from amputation, such epistemological pluralisms collapse quite easily.<sup>182</sup>

According to Marilyn Strathern, in such a postplural world any easy grounding or context is lost, and the multiplicity of perspectives fail to add up as a whole (Strathern 1992).<sup>183</sup> As a reversal of the empirical common sense of fragmentation, however, this absence of a firm ground may open up new spaces for relationality and the possibility of a *postplural anthropology* (Mohácsi and Morita 2010), which in some sense has animated my ethnography throughout this thesis.<sup>184</sup>

In stark contrast with the Trobriand Islands a century ago, in contemporary Japan, the metabolism is neither a unique perspective (of Western culture), nor a general body of knowledge (of Western science). To the extent that in Japanese clinical settings medications for chronic conditions

work best on bodies that have developed a sense of their metabolic action, molecular biologists' understandings of the metabolism incorporate the different worlds of those who need such medications to live normal lives. And to the extent that those medications facilitate people's well-being—and the revenue of companies—in different countries with incommensurable healthcare systems and medical traditions, biological and cultural differences co-constitute each other.

Anthropological categories are articulated differently at different sites, but it does not necessarily mean that they remain specifically bound to those places. They *move between* sites: forests, islands, hospitals, and laboratories, to mention just a few. Spatial unboundedness then allows us to challenge the totalizing logics of our analytical toolkits and see our categories more as arising from creative (and sometimes critical) relations between the distant and the near, the ethnographic and the theoretical.

In an ever more connected (and therefore disconnected) world, the perpetually shifting contexts and diversification of knowledge practices pose both moral and methodological challenges to anthropological analysis. Many of the notions that have been used to describe human diversity in the social and human sciences have inevitably been incorporated into the lifeworld of the people anthropologists work with, and this has resulted in new forms of interference and generated fertile grounds for differentiation. This increasing traffic between experimental and experiential worlds has prompted a greater urgency among anthropologists to explore and appreciate radical alterity by means that go beyond the conventional models of the social sciences.

If we dare to experiment with this argument, we might gain an understanding that does not divide the world between anthropologists and informants, natures and cultures, or places and concepts. While the travel

between the home and the field, or between multiple sites has been arguably an important mode of anthropological research for a long time, it is, of course, not the only one. Once we start to ethnographically attend to the traffic between theories and the "world," such movements draw our attention to other modes of articulating connectedness, such as the exchange between science and society at large, for example. As Casper Bruun Jensen and Christopher Gad noted in their staged obituary of actor-network theory: "From a postplural vantage point, theoretical perspectives are seen to be produced as much as they are producing the world. Indeed, they seem to be folded into all kinds of empirical matters on any number of different 'levels'" (Gad and Jensen 2010: 73).

When an ethnographer explores science and technology beyond the laboratory, it may involve more than simply moving between worlds: sometimes the ethnographer has to take sides. This usually means taking the side of the other: minor sciences, social worlds, or suffering patients. Yet, as metabolic togetherness highlights, it is becoming increasingly difficult to determine what is self and other, precisely because such identities are not independent either of one another or from anthropology; rather, they shape and inform each other through the very activities that are being described. In other words, technoscientific and other (e.g. anthropological) worlds are not only different, but they are also partially connected.

The relation between theory and practice is not a methodological point of reference, but part and parcel of the ethnographic project. Doing an *ethnographic theory of a metabolic disorder* is, for better or worse, another way of living together with the metabolism.





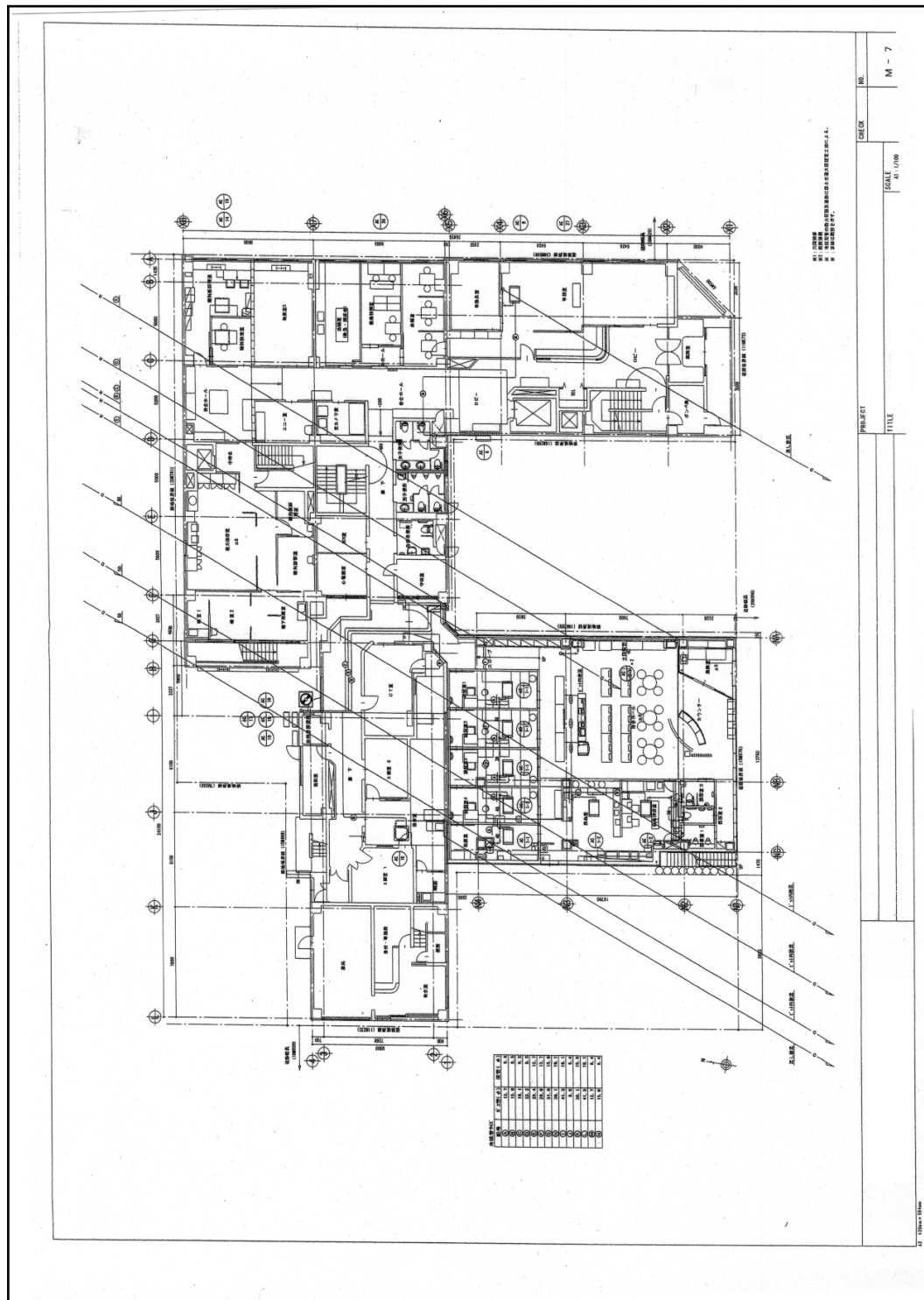


## Appendix

Appendix 1-1 Places of disease .....	250
Appendix 3-1 Clinical path.....	251
Appendix 3-2 Putting glucose on the body: step by step.....	252
Appendix 3-3a Putting glucose on the body: checklist for the beginners .....	253
Appendix 3-3b Putting glucose on the body: advanced checklist.....	254
Appendix 3-4 Putting medical images on the body .....	255
Appendix 4-1 Excerpts from the Standard Health Check-up Guidance Program .....	256
Appendix 4-2 Health check-up for metabolic syndrome (pamphlet cover) .....	258
Appendix 5-1 Adiponectin: biomarker for metabolic syndrome .....	259
Appendix 5-2 The HapMap Project.....	260
Appendix 5-3 The Biobank Japan Project .....	262
Appendix 5-4 Linking PPARs to Insulin Resistance .....	263
Appendix 6-1 Map of Sunamachi.....	265
Appendix 6-2 Map showing medical facilities in and around Sunamachi .....	266

## APPENDIX 1-1 Places of disease

Architectural layout of the 1st floor of the Suzuran Diabetes Center following its reconstruction in 1999. (Courtesy of the Center)



## APPENDIX 3-1 Clinical path

The daily routine of diabetes education summed up on the so-called critical path, an important diabetes management tool used often among experts in the Suzuran Hospital. Source: Yagi 2003:488.

### 糖尿病教育のクリティカルパス

図表：八木忠敬「クリティカルパスにおける医療教育技術の働き」  
「糖尿病教育入院を中心として」『ナラクテニクス』：2014：488-491、2003.

表1 糖尿病教育入院のクリティカルパス (患者用)

1D

名前	糖尿病教育入院 患者様用						
月日	1日目 (月)	2日目 (火)	3日目 (水)	4日目 (木)	5日目 (金)	6日目 (土)	7日目 (日)
検査	新陳代謝検査 尿検査 血糖 心電図 (午前)	血糖日内変動検査 トリゾール検査 (運動前・運動後・心電図)	心電図テスト (午後)	自律神経テスト (午後)	尿検査		
食事	食事の摂り方について 説明 (午後)						
運動	自分のペースで 歩きまわろう (午後)			自分のペースで歩きまわろう (午後)			
治療	血糖値の測定方法 インスリン						
他科受診				皮膚科 (午後)		眼科 (午前)	
10:00	インスリン治療の 説明 (午後)	自己管理について インスリン注射と 自己測定 (午後)	合併症について (午前)	日常生活の注意 インスリン療法の際の 注意点 (午後)	糖尿病の検査 検査の結果・ 治療法について	外生時及び旅行時の 注意点	
11:00	インスリン注射の 説明 (午後)	自己管理について インスリン注射と 自己測定 (午後)	合併症について (午前)	日常生活の注意 インスリン療法の際の 注意点 (午後)	糖尿病の検査 検査の結果・ 治療法について	外生時及び旅行時の 注意点	
12:00	インスリン注射の 説明 (午後)	自己管理について インスリン注射と 自己測定 (午後)	合併症について (午前)	日常生活の注意 インスリン療法の際の 注意点 (午後)	糖尿病の検査 検査の結果・ 治療法について	外生時及び旅行時の 注意点	
13:00	インスリン注射の 説明 (午後)	自己管理について インスリン注射と 自己測定 (午後)	合併症について (午前)	日常生活の注意 インスリン療法の際の 注意点 (午後)	糖尿病の検査 検査の結果・ 治療法について	外生時及び旅行時の 注意点	
14:00	インスリン注射の 説明 (午後)	自己管理について インスリン注射と 自己測定 (午後)	合併症について (午前)	日常生活の注意 インスリン療法の際の 注意点 (午後)	糖尿病の検査 検査の結果・ 治療法について	外生時及び旅行時の 注意点	
15:00	インスリン注射の 説明 (午後)	自己管理について インスリン注射と 自己測定 (午後)	合併症について (午前)	日常生活の注意 インスリン療法の際の 注意点 (午後)	糖尿病の検査 検査の結果・ 治療法について	外生時及び旅行時の 注意点	
16:00	インスリン注射の 説明 (午後)	自己管理について インスリン注射と 自己測定 (午後)	合併症について (午前)	日常生活の注意 インスリン療法の際の 注意点 (午後)	糖尿病の検査 検査の結果・ 治療法について	外生時及び旅行時の 注意点	

## APPENDIX 3-2 Putting glucose on the body: step by step

Educational material of glucose self-monitoring used at the Suzuran Center  
(©Arkray, Inc. Japan; Courtesy of the Center)

### グルコメーターダイアメーターの操作のしかた

#### 1 採血器具の準備

血糖測定を始める前に、採血器具（グルコメーターII）を準備します。

- 1 先細カパーを折り曲げるようにしてはさみます。
- 2 黄色のボタンを押しながら、針を差し込み、針先の保護キャップをわしひきします。
- 3 調節カパーを取り付けます。カパーを回して穿刺の深さを調節します。
- 4 「カチ」と音がするまで、後部のつまみを引きます。

#### 3 採血針のかたづけ

- 1 調節ボタン（黄色）を押しながら、針先を保護キャップの凹部に突き刺します。
- 2 黄色のエッジのボタンを押しながら、つまみを引きます。キャップが等しく保護キャップを置いておいてください。

#### 2 操作開始

（グルコメーターダイアメーターの操作は同じです。）

- 1 ダイアセンサー（血糖測定用電極）のアルミパックを開封します。
- 2 ダイアセンサーを挿入します。  
\*濡れた手ではさわらないようにしてください。
- 3 消毒後、採血します。
- 4 血液吸引、測定が始まります。
- 5 15秒後、血糖値が表示されます。
- 6 ダイアセンサーを抜き取ると、電源が切れます。  
\*測定の終わったダイアセンサーは再使用できません。

#### 血液の正しい吸引法




### APPENDIX 3-3a Putting glucose on the body: checklist for the beginners

Glucose self-monitoring checklist used for the training of blood sugar self-management at the Suzuran Center, for beginners (Courtesy of the Center)

#### 自己測定チェックリスト(アドバンテージ用)

自己測定前に手を洗ったか									
テストストリップ・ソフトクリックス・ランセット・酒精綿の用意が出来ているか									
ソフトクリックスを『カチッ』と音がするまでまわしたか									
テストストリップを正しく挿入したか									
テストストリップのコード番号と画面を確認したか									
手指穿刺部位のマッサージを行ったか									
穿刺部位の消毒を正しく行ったか									
消毒部位を十分に乾燥させたか									
ソフトクリックスを消毒部位に正しく当てる事が出来たか									
穿刺方法が正しいか									
血液の量は十分か・しぼり出しをしたか									
テストストリップの切れ込みに正しく血液を接触させる事が出来たか									
『ピッ』という音と共に画面が回転を始めたか									
測定値を正しく読み取ったか									
測定後アドバンテージよりテストストリップを正しく抜き取ったか									
使用後の針をソフトクリックスより取り外したか									
終了後、針は針入れに、テストストリップはゴミ入れに捨てたか									

### APPENDIX 3-3b Putting glucose on the body: advanced checklist

Glucose self-monitoring checklist used for the training of blood sugar self-management at the Suzuran Center, advanced (Courtesy of the Center)

#### 自己測定チェックリスト（グルコ カート用）

自己測定前に手を洗ったか？									
トーセンサー、トーエコー、オートクリックスP、酒精綿の用意ができているか									
オートクリックスP針を正しくつけたか？先端より針が十分に出ているか									
オートクリックスPのバネを引っ張ったか									
トーセンサーのアルミ箔の開封を正しく行うことができたか									
トーセンサーを手で直接触れたりしていないか									
トーセンサーの持ち方は正しいか									
トーセンサーをトーエコーの機械に正しく挿入することができたか									
手指穿刺部位のマッサージを行ったか									
穿刺部位の消毒を正しく行ったか									
消毒部位を十分に乾燥させたか									
オートクリックスPを消毒部位に正しく当てることができたか									
穿刺方法は正しいか									
血液の量は少なすぎないか？しぼり出しはしたか？									
トーセンサーの先端に正しく血液を接触させることができたか									
『ピー』という音を確認したか									
測定値を正しく読み取ったか									
測定後トーエコーよりトーセンサーを正しく抜き取ったか									
使用後の針をオートクリックスPより取りはずしたか									
終了後、針は針入れに、トーセンサーはゴミ入れに捨てたか									

## APPENDIX 3-4 Putting medical images on the body

The diffusion of medical technologies in Japan as compared to OECD countries, 2002. Source: OECD 2005

Chart 2.14. MRI units,  
number per million population, 2002

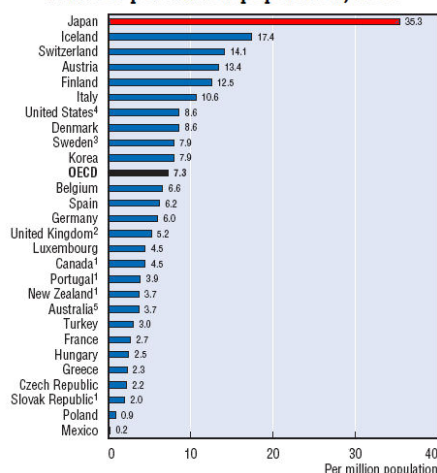


Chart 2.15. CT scanners,  
number per million population, 2002

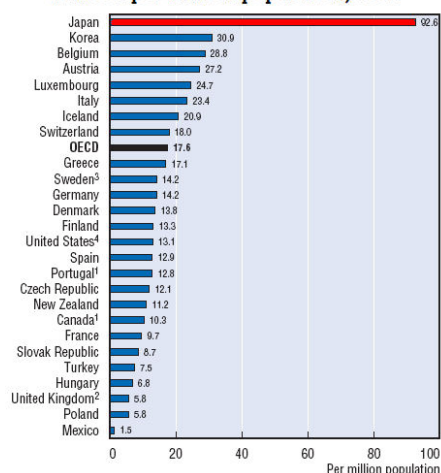


Chart 2.16. Mammographs,  
number per million population, 2002

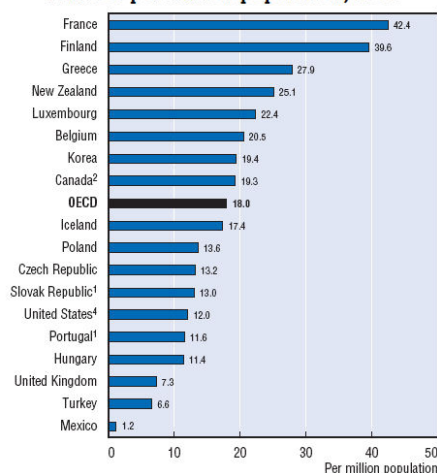
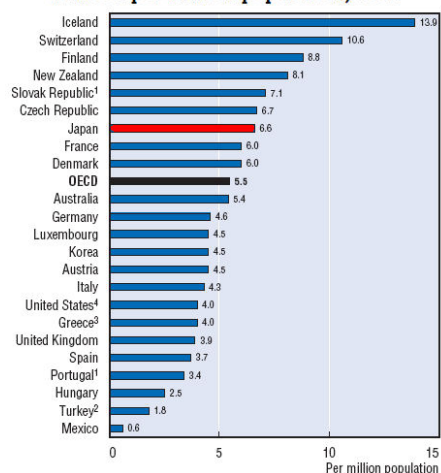


Chart 2.17. Radiation therapy equipment,  
number per million population, 2002



1. 2003.

2. 2001.

3. 1999.

4. The figures for the United States under-estimate considerably the real number of devices in that country, because they refer to the number of hospitals reporting to have at least one of these equipment rather than the total number of equipment in hospitals and in other locations (e.g., specialised clinics).

5. For Australia, the data on the number of MRI are only for those that are Medicare-eligible (60% of the total in 1999).



# APPENDIX 4-1 Excerpts from the Standard Health Check-up Guidance Program

Source: Ministry of Health, Labour and Welfare (2007)

## 標準的な健診・保健指導プログラム (確定版)

平成19年4月

厚生労働省 健康局

### 標準的な健診・保健指導プログラム

#### 第1編 健診・保健指導の理念の転換

第1章 新たな健診・保健指導の方向性	3
第2章 新たな健診・保健指導の進め方(流れ)	9
第3章 保健指導実施者が有すべき資質	11

#### 第2編 健診

第1章 内臓脂肪症候群(メタボリックシンドローム)に着目する意義	19
第2章 健診の内容	20
第3章 保健指導対象者の選定と階層化	24
第4章 健診の精度管理	29
第5章 健診データの電子化	31
第6章 健診の実施に関するアウトソーシング	37
第7章 後期高齢者等に対する健診・保健指導の在り方	40
第8章 健診項目及び保健指導対象者の選定方法の見直し	42

#### 第3編 保健指導

第1章 保健指導の基本的考え方	69
第2章 保健事業(保健指導)計画の作成	73
第3章 保健指導の実施	82
第4章 保健指導の評価	110
第5章 地域・職場における保健指導	115
第6章 保健指導の実施に関するアウトソーシング	119

#### 第4編 体制・基盤整備、総合評価

第1章 人材育成体制の整備	133
第2章 最新の知見を反映した健診・保健指導内容の見直しのための体制整備	135
第3章 健診・保健指導の実施・評価のためのデータ分析とデータ管理	138

(添付資料)

- 関係学会におけるガイドライン(抜粋)
- 「健診・保健指導」の研修ガイドライン
- 健康診査における精度管理の在り方

(別冊)

- 保健指導事例集
- 保健指導における学習教材集

#### 第2章 新たな健診・保健指導の進め方(流れ)

##### (1) 計画の作成

健診・保健指導計画作成のために、各種データ分析(男女別・年代別の健診結果、有所病状況、内臓脂肪症候群(メタボリックシンドローム)該当者、予備群及びリスクの重症状況、対象となる被保険者数・被扶養者数及び過去の健診受診者数・未受診者数等の把握、医療費データ(レセプト等)、要介護度データ等)を行い、集団の特性や健康課題を把握し、具体的な目標を定めた年次計画を策定し、毎年の健診・保健指導事業を実施していくことが必要である。

また、未受診者、治療中断者等に対する支援方法についても、集団特性に併せ、創意工夫をし、計画の中に盛り込んでいく必要がある。

##### (2) 健診の実施、保健指導対象者の選定・階層化

健診結果及び質問項目を基に保健指導対象者の選定・階層化を行うことが必要である。保健指導の対象者は、健診受診者すべてであるが、保健指導の必要性の度合いによって階層化を行う。階層化は、①「情報提供」のみを行う、②「情報提供」に加え「動機づけ支援」を行う、③「情報提供」に加え「積極的支援」を行う、の3段階に区分して、保健指導を実施する。

##### (3) 保健指導

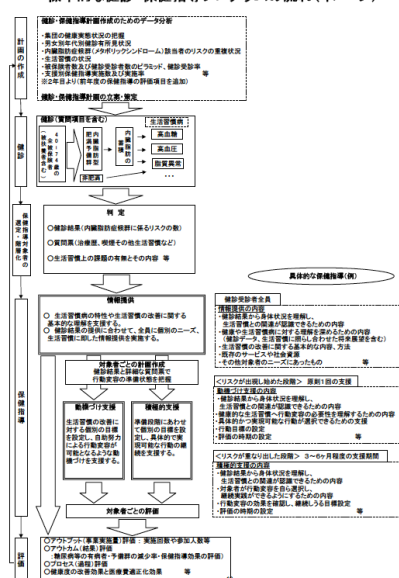
健診結果及び質問項目により階層化された対象者に、適切な保健指導(「情報提供」、「動機づけ支援」、「積極的支援」)を行うことが必要である。

##### (4) 評価

健診・保健指導の結果を基に、ストラクチャー<sup>1</sup>(構造)評価(実施体制、施設・設備の状況)、プロセス(過程)評価(健診・保健指導実施者の研修等)、アウトプット(事業実施量)評価(実施回数、参加人数等)、アウトカム(結果)評価(糖尿病等の生活習慣病有病者、予備群の減少率、健診データの改善、健康度の改善効果、医療費の適正化効果等)を行い、次年度の健診・保健指導計画につなげることが必要である。

<sup>1</sup> ストラクチャー：構造。健診・保健指導を実施する際の構成因子。物的資源(施設、設備、資金等)、人的資源(職員数、職員の資質等)、組織的資源(スタッフ組織、相互役割の仕組み、償還制度等)。

### 内臓脂肪型肥満に着目した生活習慣病予防のための標準的な健診・保健指導プログラムの流れ(イメージ)



第1章 内臓脂肪症候群（メタボリックシンドローム）に着目する意義

平成17年4月に、日本内科学会等内科系8学会が合同でメタボリックシンドロームの疾患概念と診断基準を示した。

これは、内臓脂肪型肥満を共通の要因として、高血糖、脂質異常、高血圧を呈する病態であり、それぞれが重複した場合は、虚血性心疾患、脳血管疾患等の発症リスクが高く、内臓脂肪を減少させることでそれらの発症リスクの低減が図られるという考え方を基本としている。

すなわち、内臓脂肪型肥満に起因する糖尿病、高脂血症、高血圧は予防可能であり、また、発症してしまった後でも、血糖、血圧等をコントロールすることにより、心筋梗塞等の心血管疾患、脳梗塞等の脳血管疾患、人工透析を必要とする腎不全などへの進展や重症化を予防することは可能であるという考え方である。

内臓脂肪症候群（メタボリックシンドローム）の概念を導入することにより、内臓脂肪の蓄積、体重増加が血糖や中性脂肪、血圧などの上昇をもたらすとともに、様々な形で血管を損傷し、動脈硬化を引き起こし、心血管疾患、脳血管疾患、人工透析の必要な腎不全などに至る原因となることを詳細にデータで示すことができるため、健診受診者にとって、生活習慣と健診結果、疾病発症との関係が理解しやすく、生活習慣の改善に向けての明確な動機づけができるようになると思われる。

第2章 健診の内容

（1）健診項目（検査項目及び質問項目）

1）基本的考え方

○ 今後の新たな健診においては、糖尿病等の生活習慣病、とりわけ内臓脂肪症候群（メタボリックシンドローム）の該当者・予備群を減少させるため、保健指導を必要とする者を的確に抽出するための健診項目とする。

○ また、質問項目は、①生活習慣病のリスクを評価するためのものであること、②保健指導の励行化と健診結果を通知する際の「情報提供」の内容を決定する際に活用するものであることという考え方に基づくものとする。

○ なお、過去の健診項目との比較や健診実施体制の確保の容易性から、既に実施されている他の健康診断・健康診査等（介護保険法に基づく地域支援事業を含む）との関係について整理することが必要である。

2）具体的な健診項目

特定健康診査の項目のうち、「健診対象者の全員が受ける基本的な健診」と「医師が必要と判断した場合に選択的に受ける詳細な健診」の項目を以下のとおりとする（[別紙1](#)参照）。

①基本的な健診の項目

質問項目、身体計測（身長、体重、BMI、腹囲（内臓脂肪面積））、理学的検査（身体診察）、血圧測定、血液化学検査（中性脂肪、HDLコレステロール、LDLコレステロール）、肝機能検査（AST（GOT）、ALT（GPT）、γ-GT（γ-GTP））、血糖検査（空腹時血糖又はHbA1c検査）、尿検査（尿糖、尿蛋白）

※ 血糖検査については、HbA1c検査は、過去1～3か月の血糖値を反映した血糖値のコントロールの指標であるため、保健指導を行う上で有効であるとともに、総食による健診受診を要診者に対して、事前に通知していたとしても、食事量を制限した上で健診を受診することにより、必ずしも空腹時における採血が行えないことから、空腹時血糖とHbA1c検査の両者を実施することが望ましい。特に、糖尿病が疑われる保険者に対しては、HbA1cを必ず行うことが望ましい。

②詳細な健診の項目

心電図検査、眼底検査、貧血検査（赤血球数、血色素量〔ヘモグロビン値〕、ヘマトクリット値）のうち、一定の基準（[別紙2](#)）の下、医師が必要と判断したものを選択。

③その他の健診項目

40～74歳を対象とする健康診査においては、それぞれの法令の趣旨、目的、制度に基づき、①の基本的な健診項目以外の項目を実施する。中でも、血清尿酸、血清クレアチニン検査、HbA1c等については、必要に応じ実施することが望ましい。

## APPENDIX 4-2 Health check-up for metabolic syndrome (pamphlet cover)

Source: [https://www.tkhs.co.jp/img/HE320140\\_360.jpg](https://www.tkhs.co.jp/img/HE320140_360.jpg) (accessed on August 15, 2017).



## APPENDIX 5-1 Adiponectin: biomarker for metabolic syndrome

Source: Excerpt from Trujillo ME, Scherer PE (Albert Einstein College of Medicine, Bronx, NY, USA). Adiponectin—journey from an adipocyte secretory protein to biomarker of the metabolic syndrome (Review). *J Intern Med* 2005; 257: 167–175.

**Abstract:** Adiponectin is an adipocyte-derived hormone that was discovered in 1995. Unlike leptin, which was identified around the same time, the clinical relevance of adiponectin remained obscure for a number of years. However, starting in 2001, several studies were published from different laboratories that highlighted the potential antidiabetic, antiatherosclerotic and anti-inflammatory properties of this protein complex. Methods to measure the protein with high throughput assays in clinical samples were developed shortly thereafter, and as a result hundreds of clinical studies have been published over the past 3 years describing the role of adiponectin in endocrine and metabolic dysfunction. Furthermore, adiponectin research has expanded to include a role for adiponectin in cancer and other disease areas. Although it is an impossible task to summarize the findings from all these studies in a single review, we aim to demonstrate the utility of circulating adiponectin as a biomarker of the metabolic syndrome. Evidence for this relationship will include how decreased levels of plasma adiponectin ('hypoadiponectinaemia') are associated with increased body mass index (BMI), decreased insulin sensitivity, less favourable plasma lipid profiles, increased levels of inflammatory markers and increased risk for the development of cardiovascular disease. Therefore, adiponectin levels hold great promise for use in clinical application serving as a potent indicator of underlying metabolic complications.

Keywords: ACRP30, atherosclerosis, insulin sensitivity, PPARc.

## APPENDIX 5-2 The HapMap Project

Source: Electronic document, <http://www.hapmap.org> (accessed on June 8, 2008)

The International HapMap Project is a multi-country effort to identify and catalog genetic similarities and differences in human beings. Using the information in the HapMap, researchers will be able to find genes that affect health, disease, and individual responses to medications and environmental factors. The Project is a collaboration among scientists and funding agencies from Japan, the United Kingdom, Canada, China, Nigeria, and the United States. All of the information generated by the Project will be released into the public domain. The goal of the International HapMap Project is to compare the genetic sequences of different individuals to identify chromosomal regions where genetic variants are shared. By making this information freely available, the Project will help biomedical researchers find genes involved in disease and responses to therapeutic drugs. In the initial phase of the Project, genetic data are being gathered from four populations with African, Asian, and European ancestry. Ongoing interactions with members of these populations are addressing potential ethical issues and providing valuable experience in conducting research with identified populations. Public and private organizations in six countries are participating in the International HapMap Project. Data generated by the Project can be downloaded with minimal constraints. The Project officially started with a meeting in October 2002 and is expected to take about three years.

### What is the HapMap?

The HapMap is a catalog of common genetic variants that occur in human beings. It describes what these variants are, where they occur in our DNA, and how they are distributed among people within populations and among populations in different parts of the world. The International HapMap Project is not using the information in the HapMap to establish connections between particular genetic variants and diseases. Rather, the Project is designed to provide information that other researchers can use to link genetic variants to the risk for specific illnesses, which will lead to new methods of preventing, diagnosing, and treating disease.

The DNA in our cells contains long chains of four chemical building blocks -- adenine, thymine, cytosine, and guanine, abbreviated A, T, C, and G. More than 6 billion of these chemical bases, strung together in 23 pairs of chromosomes, exist in a human cell. (...) The genetic sequences of different people are remarkably similar. When the chromosomes of two humans are compared, their DNA sequences can be identical for hundreds of bases. But at about one in every 1,200 bases, on average, the sequences will differ. One person might have an A at that location, while another person has a G, or a person might have extra bases at a given location or a missing segment of DNA. Each distinct "spelling" of a chromosomal region is called an allele, and a collection of alleles in a person's chromosomes is known as a genotype.

Differences in individual bases are by far the most common type of genetic variation. These genetic differences are known as single nucleotide polymorphisms, or SNPs (pronounced "snips"). By identifying most of the approximately 10 million SNPs

estimated to occur commonly in the human genome, the International HapMap Project is identifying the basis for a large fraction of the genetic diversity in the human species.

For geneticists, SNPs act as markers to locate genes in DNA sequences. Say that a spelling change in a gene increases the risk of suffering from high blood pressure, but researchers do not know where in our chromosomes that gene is located. They could compare the SNPs in people who have high blood pressure with the SNPs of people who do not. If a particular SNP is more common among people with hypertension, that SNP could be used as a pointer to locate and identify the gene involved in the disease.

However, testing all of the 10 million common SNPs in a person's chromosomes would be extremely expensive. The development of the HapMap will enable geneticists to take advantage of how SNPs and other genetic variants are organized on chromosomes. Genetic variants that are near each other tend to be inherited together. For example, all of the people who have an A rather than a G at a particular location in a chromosome can have identical genetic variants at other SNPs in the chromosomal region surrounding the A. These regions of linked variants are known as haplotypes.

In many parts of our chromosomes, just a handful of haplotypes are found in humans. In a given population, 55 percent of people may have one version of a haplotype, 30 percent may have another, 8 percent may have a third, and the rest may have a variety of less common haplotypes. The International HapMap Project is identifying these common haplotypes in four populations from different parts of the world. It also is identifying "tag" SNPs that uniquely identify these haplotypes. By testing an individual's tag SNPs (a process known as genotyping), researchers will be able to identify the collection of haplotypes in a person's DNA. The number of tag SNPs that contain most of the information about the patterns of genetic variation is estimated to be about 300,000 to 600,000, which is far fewer than the 10 million common SNPs.

Once the information on tag SNPs from the HapMap is available, researchers will be able to use them to locate genes involved in medically important traits. Consider the researcher trying to find genetic variants associated with high blood pressure. Instead of determining the identity of all SNPs in a person's DNA, the researcher would genotype a much smaller number of tag SNPs to determine the collection of haplotypes present in each subject. The researcher could focus on specific candidate genes that may be associated with a disease, or even look across the entire genome to find chromosomal regions that may be associated with a disease. If people with high blood pressure tend to share a particular haplotype, variants contributing to the disease might be somewhere within or near that haplotype.

## APPENDIX 5-3 The Biobank Japan Project

Source: Electronic document, <http://www.src.riken.go.jp/english/project/person/index.html> (accessed June 8, 2008)

A major goal of the Human Genome Project is to apply the research results to healthcare. As the research progresses, the following may become possible.

1. Researchers will have a detailed understanding of the mechanisms causing disease and its symptoms, including diseases of unknown cause for which physicians cannot even begin developing a cure at present.
2. Researchers are expected to be able to develop new diagnostic methods and innovative drugs (through evidence-based drug development), by targeting the genes, proteins or other biological components that are proven to be the cause of the disease or symptom (evidence).
3. Personalized medicine, where the treatment is tailored to the individual, may become possible, for example through different drug treatments for different patients with the same diagnosis or similar symptoms, on the basis of subtle differences in each patient.
4. In the future, it may be possible to determine how susceptible each individual is to various diseases and, by adjusting the lifestyle of each individual based on this information, to prevent disease onset, delay disease onset, or achieve rapid diagnosis and treatment of a disease

The BioBank Japan Project on the implementation of personalized medicine:

We are well aware that each individual differs in terms of whether they are susceptible to a particular disease or whether they are more likely to suffer side effects from drug treatment. We currently accept this concept by thinking of it as differences in an individual constitution. Instead of this vague concept, researchers are now starting to provide scientific evidences based on differences in genetic variations in each individual. For example, we ascribe someone's tolerance for alcohol to their constitution, but it is well known that alcohol tolerance depends on genetic differences in an enzyme that breaks down alcohol in the body.

Around the world, researchers are developing databases with information on these types of differences in our genetic code. In Japan, the BioBank Japan Project on the implementation of personalized medicine (Project Leader: Yusuke Nakamura) have begun in fiscal year of 2003 with the support of the Ministry of Education, Culture, Sports, Science and Technology (MEXT). The project aims for construction of basic information for personalized medicine.

The SNPResearchCenter functions as a core research organization for the personalized medicine project and plays a central role in genetic analysis. We will work in cooperation with patients by the words "Your understanding for our future" to provide better healthcare options for the benefit of patients.

## APPENDIX 5-4 Linking PPARs to Insulin Resistance

Source: Patlak, Margie. 2002. *New Weapons to Combat an Ancient Disease: Treating Diabetes*. FASEB J. 16(14):1853e.

Keywords: Japan, Takeda, PPAR activators, glitazones

Steps on the path linking one of these receptors, called PPAR gamma, to type 2 diabetes were first taken in the 1970s by a Japanese pharmaceutical company called Takeda. Because intensive breeding efforts had successfully led to the development of type 2 diabetic mice, researchers at Takeda had a way to easily screen for anti-diabetic compounds. Takashi Soda and his colleagues tested a number of potential drugs on these diabetic animals to see if they lowered their blood sugar. One drug, called ciglitazone, not only lowered blood sugar, but also caused a remarkable drop in insulin production and triglyceride levels in type 2 diabetic animals and increased their sensitivity to insulin. Unlike any other diabetic medication on the market at that time, ciglitazone seemed to counter the insulin resistance and excessive insulin production that underlies type 2 diabetes! The drug also tackled some aspects of the metabolic syndrome, such as high triglyceride levels and impaired glucose tolerance, in obese non-diabetic animals. These findings suggested the drug could not only be used to treat diabetes, but pre-diabetes as well, perhaps preventing or delaying the onset of diabetes and its complications.

The Japanese researchers published their findings in 1983. This prompted excitement in the pharmaceutical research community. Scientists at several drug companies directed their efforts toward tweaking various chemical portions of ciglitazone to create more potent anti-diabetes drugs, known as glitazones. But no one knew how these drugs worked.

That riddle was solved by molecular biologists at the Glaxo Research Institute in North Carolina, who were trying to figure out what causes fat cells to mature. Other scientists had shown that PPAR gamma was produced in large amounts by mature fat cells. In addition, researchers had reported that glitazones induced precursor fat cells (pre-adipocytes) to mature into fat cells. Putting two and two together, Steven Kliewer and his colleagues used some clever laboratory manipulations to show, in 1995, that glitazones activated PPAR gamma. This discovery gave researchers a major new target for anti-diabetes drugs—compounds that could activate PPAR gamma. Two such drugs, rosiglitazone (Avandia) and pioglitazone (Actos), came on the market in 1999. During this same year, researchers reported that people born with a genetic mutation that disables PPAR gamma all show the hallmarks of the metabolic syndrome—insulin resistance, diabetes, high blood pressure, low HDL cholesterol and high triglyceride levels. This finding further supported the notion that drugs that activate PPAR might be effective at preventing or treating diabetes.

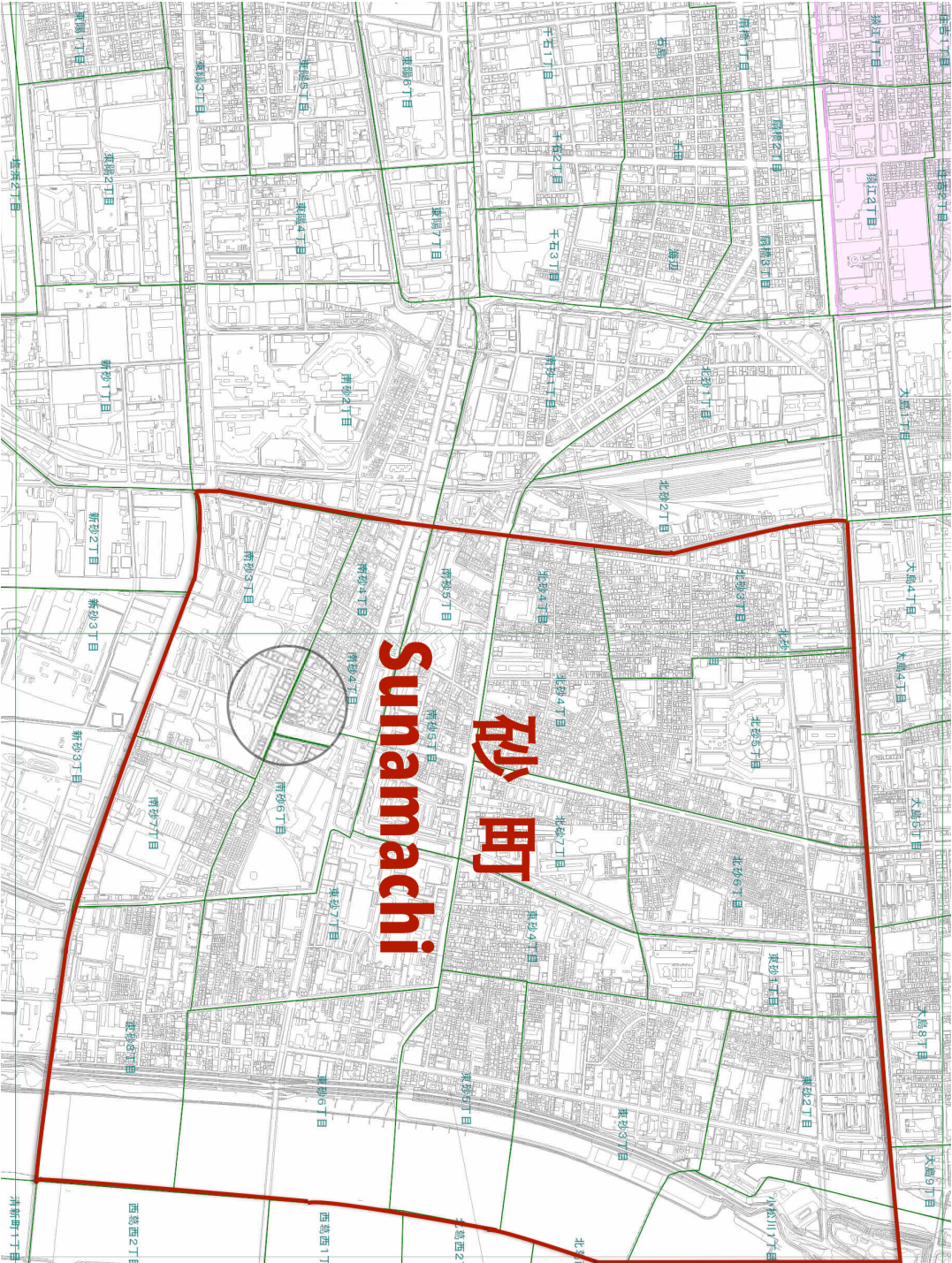
Indeed, one glitazone drug given to type 2 diabetes-prone rodents prevented them from developing the disorder. It also prevented the loss of insulin-producing cells in the pancreas that is normally seen in the late stages of type 2 diabetes in these animals (and in humans). Researchers are currently testing Avandia and Actos to see if they can prevent type 2 diabetes or its complications in people. In the meantime, millions of



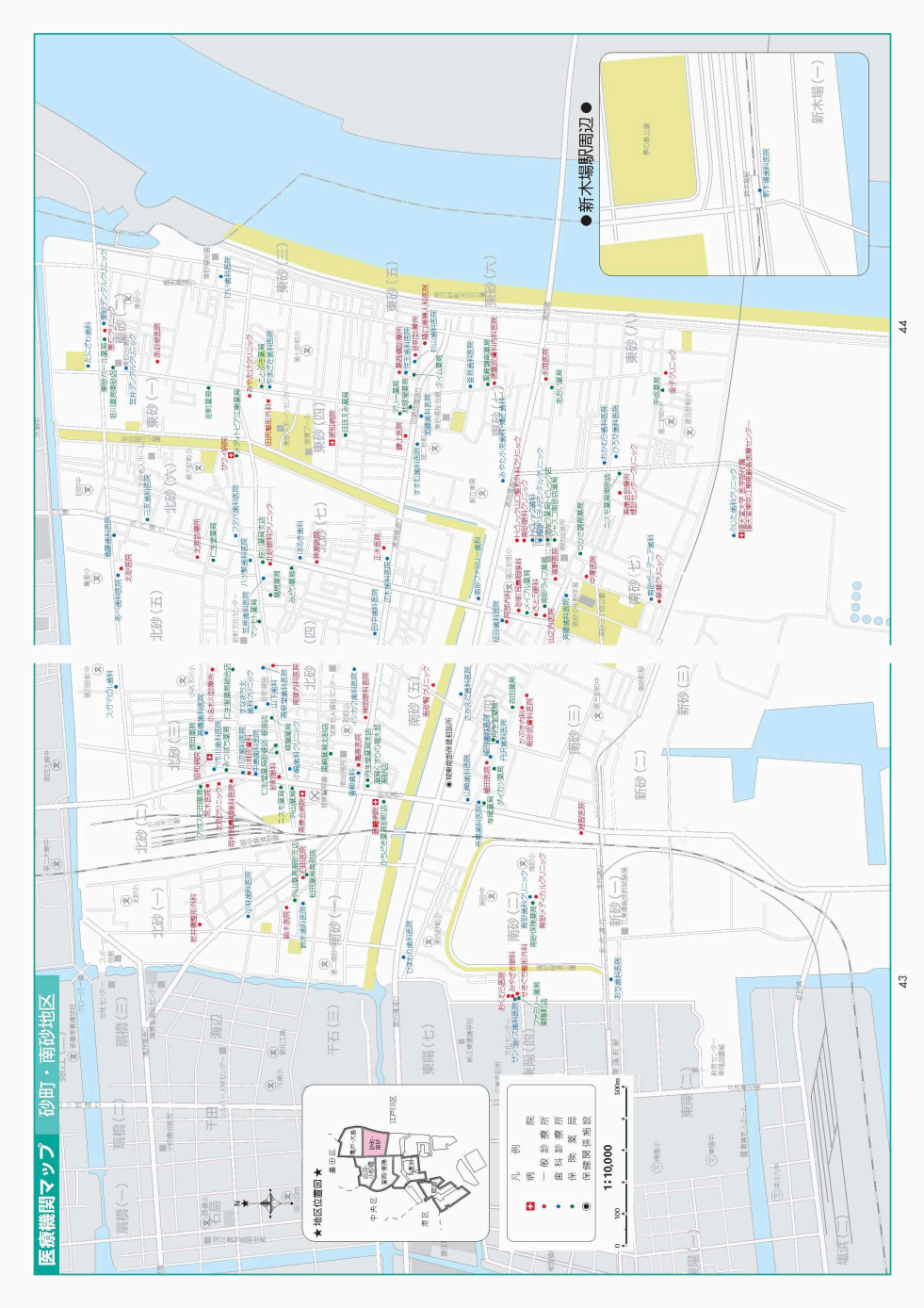
people in this country take these drugs because they have already proven so effective as treatments for this condition. These drugs reduce type 2 diabetics' blood sugar levels by about a quarter. Actos prompts a nearly 20-percent drop in type 2 diabetics' triglyceride blood levels, while boosting HDL-cholesterol levels by 13 percent. Avandia causes a drop in insulin levels that may be beneficial over the long term.

New PPAR activators, including those that also activate PPAR alpha and/or delta, are expected to be even more effective than the glitazones currently available. Researchers are currently testing these drugs in animals and humans. Basic research has also uncovered other drug targets for type 2 diabetes, including molecules that carry glucose into cells and gut proteins that trigger insulin release. Drugs that boost the actions of these molecules are showing promise in initial tests as well.

APPENDIX 6-1 Map of Sunamachi



APPENDIX 6-2 Map showing medical facilities in and around Sunamachi



## Notes

<sup>1</sup> It seems to me fair to say that following the crisis of cultural representation this emphasis on human diversity is probably one of the few things that most anthropologists would agree on.

<sup>2</sup> Fieldwork notes, Shitamachi Clinic, November 12, 2002.

<sup>3</sup> From a historical point of view, one may see this disciplinary divide as a Fordist model of doing science confirmed by the numerous edited volumes, textbooks, monographs and special issues in academic journals about a wide variety of illness experiences around the world (see e.g. Ikeda and Okuno 2007; Manderson and Smith-Morris 2010; Pachter 1993).

<sup>4</sup> For an introduction to the narrative model in medical anthropology, see (Good 1977); for a more theoretically driven overview, see (Young 1982). For Japanese case studies, see (Ohnuki-Tierney 1984) and (Namihira 1990), among others.

<sup>5</sup> This, in turn, has left other arguments of medical anthropology in a "theoretical void" well into the 1990s. Well-known examples include Michael Taussig's often-cited but never really further elaborated article on the reification of the patient or the ethnomethodological work of Horacio Fabrega, among others (Fabrega and Silver 1973; Taussig 1980).

<sup>6</sup> The Diagnostic and Statistical Manual of Mental Disorders (DSM) is published and revised in roughly every 10-15 years by the American Psychiatric Association, but used worldwide in mental healthcare and psychiatric pharmacology.

<sup>7</sup> For a recent review of the term and its uses in the social sciences of medicine, see (Conrad and Waggoner 2014).

<sup>8</sup> As Chris Feudtner, a practicing pediatrician and historian of diabetes summarized, the chronicity of this condition and the epidemic speed it has spread around the world is an "irony of modern technology." While technological advancements in food processing and transportation have according to Feudtner, pushed large number of people into a state of increased levels of glucose, which, in turn, requires a multitude of screening technologies and pharmaceuticals to keep it at bay (Feudtner 2011: 90).

<sup>9</sup> For a Japanese overview of the ontological turn, see the special issue titled 「人類学のゆくえ」 (The future of anthropology) in the journal 『現代思想』 (*Gendai Shisō*), February, 2016 (Nakazawa 2016); for an English discussion of parallel tendencies in Japanese anthropology, see (Jensen and Morita 2012).

<sup>10</sup> For a recursive perspective on *mono*, see the edited volume *The Anthropology of Mono* by (Kawai and Tokoro 2011) that collects case studies of the culture of "things" from around the world by Japanese anthropologists. Medical anthropologist Judith Farquhar and cultural historian Qicheng Zhang, in their *Ten Thousand Things: Nurturing Life in Contemporary Beijing* provide a parallel, if not identical, illustration of the complicated entanglements of people and things in the Chinese context (Farquhar and Zhang 2012). See also François Jullien's widely cited comparative philosophical study on the *The Propensity of Things* in Chinese history (Jullien 1995).

<sup>11</sup> As has been aptly pointed out by Casper Bruun Jensen, ANT's affinity with the *activity* of actors—that there is no telling of what they will become or will be doing—fits all too well with the anthropological interest in spirits, magic and shamanistic worlds that operate on similarly unpredictable principles (Jensen 2016).



<sup>12</sup> In the original: 「高カロリーの食生活を続けたとき、欧米人の体はそれに対応してインスリンをたくさん分泌するので、食べた分がそのまま体に脂肪としてつきます。ところが日本人が同じような食生活をする、体内のインスリンの分泌が追いつかなくなります。そのため、簡単にいうと、余分に食べた分が血液中に糖として残ることになります。つまり、栄養過多が続くと、ある程度以上は太らない代わりに糖尿病になってしまうのです。モンゴロイドが糖尿病になりやすいもうひとつの理由は、飢餓に強い遺伝的な要素をもっているということです」 (Yazawa Science Office 2003: 52)。

<sup>13</sup> Diabetes is a chronic condition that occurs when the body cannot produce enough insulin or cannot use insulin<sup>1</sup>, and is diagnosed by observing raised levels of glucose in the blood. Insulin is a hormone produced in the pancreas; it is required to transport glucose from the bloodstream into the body's cells where it is used as energy. The lack, or ineffectiveness, of insulin in a person with diabetes means that glucose remains circulating in the blood. Over time, the resulting high levels of glucose in the blood (known as hyperglycaemia) causes damage to many tissues in the body, leading to the development of disabling and life-threatening health complications (International Diabetes Federation 2015: 22).

<sup>14</sup> *Type 1 diabetes* is an autoimmune disease triggered by infection or other agents, mostly affecting children and adolescents. *Type 2 diabetes*, on the other hand, is a chronic condition that mostly, but not exclusively, develops during adulthood and is associated with genetic causes and lifestyle. It is for this reason that in Japan diabetes has been labelled as a lifestyle-disease (*seikatsu shūkan byō*). Type 2 diabetes accounts for 90% of all cases worldwide. The third major type, *gestational diabetes* affects women during pregnancy and, contrary to the other two types, recedes in most cases after giving birth.

<sup>15</sup> For reviews of the anthropological literature on diabetes see (Ferzacca 2012) and (Lieberman 2004). Needless to say, both of these reviews are heavily weighted toward North American research, so in this introduction I try to make up for the lack, at least with adding European and Japanese work to the list.

<sup>16</sup> For historical accounts of diabetes see Robert Tattersall's overview from a Euro-American perspective (2009), and Tarui Seiichiro's biography of the disease in the Japanese context (2009). Somewhat closer to the specific trajectories of this thesis are Christiane Sinding's analytical take on the emergence of the discipline of endocrinology (2004); Chris Feudtner's historical study on the transformation of diabetes from an acute condition to a chronic illness (2003) and Kosaka Kinori's overview of the changing concept of diabetes in Japan (1994).

<sup>17</sup> The second volume of *Human Science of Lifestyle Related Diseases* (2012), especially Chapter 11 on medical anthropology, provides a more general overview of research conducted and published in Japanese in this field (Tsujiuchi 2012).

<sup>18</sup> See more on these epidemiologically influenced debates in the context of genetic research in Japan in Chapter 5.

<sup>19</sup> For an early review of nutritional epigenetic, see (Landecker 2011).

<sup>20</sup> As a short piece in the Diabetes & Endocrinology edition of *The Lancet* notes, technologies of quantification travel along the statistical highways of difference and variation: ""Although there's heterogeneity within diet, physical activity, and disease outcome within Europe, the variation between countries and continents around the world is much greater (...). The challenge is how do we move from effectively studying variation within populations in Europe to studying variation between populations, bringing in data from researchers in all different continents around the world?" (Mohammadi 2015)

<sup>21</sup> Perhaps the most telling of this is the fact that there is now a category called "Diabetes Quality of Life" (DQoL) used widely in the epidemiology literature.

- <sup>22</sup> 平成24年国民健康・栄養調査（厚生労働省）National Health and Nutrition Survey, 2012 (Ministry of Health, Labour and Welfare) at <http://www.mhlw.go.jp/stf/houdou/0000032074.html> (accessed on September 15, 2017).
- <sup>23</sup> A global comparative analysis projected health expenditures for diabetes at \$22,150,916 in 2010, making Japan the third biggest market of diabetes after the United States and Germany (Zhang et al. 2011).
- <sup>24</sup> See (Yazaki and Kadowaki 2006) for an overview of the health policy and genetic research on diabetes in Japan.
- <sup>25</sup> For a critical assessment of these issues, see the special issue, *Bodies on Trial* in the journal *Body & Society* edited by Marc Berg and Madeleine Akrich (2004). More recent works in the genre of laboratory studies have tried to deal with the methodological problems mentioned here (see e.g. Myers 2015; Suzuki 2018).
- <sup>26</sup> Communication theory and phenomenological approaches are two key areas that influenced medical anthropologists' notion of human singularity (see e.g. Fisher and Todd 1983; Yamazaki and Nishizaka 1997).
- <sup>27</sup> In the tradition of ethnomethodology and discourse analysis several studies have highlighted the practical embeddedness of language in the clinical encounter between patient and doctor. Nevertheless, here as elsewhere, it is the communicative *event* that medical knowledge is supposed to be situated in.
- <sup>28</sup> For important case studies in this genre, see Karen Barad's work on quantum physics (2007), Annemarie Mol's praxiography of atherosclerosis in a Dutch hospital (2002a) or Eben Kirksey's ethnographic research among taxonomy specialists in Central and North America (2015). For a recent attempt to engage STS with medical anthropology through a practice-oriented approach, see (Yates-Doerr 2017).
- <sup>29</sup> For an introduction to the main currents of this research, see 田辺・増田編 2002 and 福島 2010 (both in Japanese). For an English summary, see Morita and Jensen 2012 (359–62). See also 池田 2001 for a medical anthropological take on the issue.
- <sup>30</sup> The interdependence of practices and ideas is, of course, a classic theme in the history of anthropology starting from Mauss' treatment of the gift, or Evans-Pritchard's examination of witchcraft in Central Africa (Evans-Pritchard 1937; Mauss 1950 [1925]). Contemporary Japanese anthropologists are, however, probably more indebted to the theorizing of practice by Pierre Bourdieu (1977).
- <sup>31</sup> For more specific discussion of the spatial arrangement of labor through technological practices in medicine see (Campbell and Ikegami 1998) or (Masuda et al. 2001).
- <sup>32</sup> In the original: 「（…）知が実践のものに内在しており…。知識は本に書かれたようなモノではなく生きた身体に宿っている（…）すなわち、＜実践知＞と呼んでいこう。私達は知識を操作しているのではなく知識をいきているのである。」
- <sup>33</sup> For a detailed philosophical argument for a social scientific approach to *disease*, as opposed to the more conventional anthropological division between *illness* and *disease*, see (Mol 2002a: 9–12).
- <sup>34</sup> This transformation is usually associated with the so called long-term care insurance system (*kaigō hoken*), which was introduced in April 2000, but there are many other measures that preceded and prepared it stretching out for more than twenty years in time (Olivares-Tirado and Tamiya 2014; Ōmori 2014).

<sup>35</sup> Occupied after the Meiji Restoration and colonized gradually during the second half of the 19th century, Hokkaido has been historically viewed as "the laboratory of Japan". To this day, it is often viewed as a frontier space (Hansen 2014). The "youngest" of the four major Japanese islands, it continues to be under special governance by two separate political bodies: a prefectural government (actually not an integral part of the basic administrative system of Japan) and the Hokkaido Development Bureau, an affiliated agency of the central government. It is known to serve as the experimental site for many companies—including medical device suppliers and pharmaceutical manufacturers—introducing their new products. My Japanese friends often asked me why I have chosen Hokkaido for my fieldwork. "Hokkaido has no history. Hokkaido is not the real Japan. If you want to see Japanese culture, you should go to Honshū." This resonates well with what Heather Swanson describes in her discussion of the technological exchanges of salmon fishery between the American West and Hokkaido. She writes: "When we look at how comparisons are embedded in Hokkaido's landscapes, we see an ostensibly 'Japanese' landscape that is radically cosmopolitan; one that is made not by some internal, self-produced logic, but by a set of comparative encounters in which comparisons continually bring other landscapes and other cultures inside that which is called Hokkaido" (Swanson 2015: 40). Such comparisons between Hokkaido, the rest of Japan and North America were also instrumental in the establishment of the Suzuran Center whose director was an admirer of the world famous Joslin Clinic in Boston.

<sup>36</sup> Interview with Dr. Komata, Suzuran Hospital, August 20, 2003.

<sup>37</sup> Interview with Dr. Mihara, Suzuran Hospital, September 1, 2003.

<sup>38</sup> For a more detailed explanation of the abdominal CT, see Chapter 4.

<sup>39</sup> On the formation of networks in medical research see the work of Bruno Latour on Pasteur and Paul Rabinow's case study of a genetic research on diabetes (Latour 1988; Rabinow 1999). My conception of 'alliances' in medicine bears an affinity to Steven Shapin and Simon Schaffer's description of the generation of experimental knowledge through the forming of allies around Boyle's air-pump (Shapin and Schaffer 1985).

<sup>40</sup> Fieldwork notes, Suzuran Hospital, May 17, 2003.

<sup>41</sup> Iwamizawa is a small town in Central Hokkaido, about 50 kilometers from the major city of Sapporo.

<sup>42</sup> *Complying* with the treatment regimen may be a better translation of this sentence, or at least the intention of Imamura-san's wife. The reason I left this literal translation was to stress the fact that disease itself has come to stand for treatment.

<sup>43</sup> The dissertation was completed in the second half of 2017.

<sup>44</sup> The centrality of nutrition therapy in diabetes care has been discussed exhaustively by anthropologists. See e.g., the work of Steve Ferzacca (2004) in the U.S. and Simon Cohn (1997) in the U.K. For more general insights on the role of nutrition therapy in metabolic disorders, Emily Yates-Doerr (2015; especially Chapter 3) and Harris Solomon (2016; especially Chapter 4) provide superb analysis of Guatemalan and Indian case studies, respectively.

<sup>45</sup> One might take these relations between the everyday and the scientific as an occasion for an anthropology of disease, something I am trying to elaborate here. But such relations are very firmly embedded in the official (or, say, scientific) knowledge of nutrition too, as a definition from the Encyclopedia of Food and Culture plausibly indicates: [Nutrition is] "the daily intake of a variety of foods provides energy and nutrients that are essential to the health and well-being of an individual. The relationships among food intake, nutrition, and health define the field of nutrition. More fully, nutrition is the study of food, its nutrients and chemical components, and how these constituents act and interact within the body to affect health and disease." (Fung and Stallings 2003: 588)

<sup>46</sup> Fieldwork notes, Suzuran Hospital, September 25, 2003.

<sup>47</sup> In contrast to the U.S. and Europe, where food pyramids are used for modeling the hierarchy of nutrients, in Japan, at the time of my research, food circles were much more prevalent in the popular literature of diet therapy giving the impression of a balanced whole rather than one of hierarchical clusters.

<sup>48</sup> For an auto-ethnographic account on hospital food in Japan, see (Runestad 2016).

<sup>49</sup> In the original: 「食事療法は糖尿病治療の基本です。いかに薬をうまく使っても食事が適切でないと糖尿病は克服できません。しかし、現在の糖尿病の食事は、健康な方が通常の生活をするのに必要なカロリーや栄養素のバランスのとれた良い食事なのですから、早く慣れましょう。」

<sup>50</sup> In its simplest form, carbohydrate and protein each provide 4 calories per gram, while fat contains 9 calories.

<sup>51</sup> For further dimensions of the socio-material practices around food in diabetes care see Chapter 6.

<sup>52</sup> These randomized controlled trials are not at all unique to diabetes. The treatment of other chronic conditions have been likewise comprehensively studied in carefully designed trials (see e.g. Willems 2000).

<sup>53</sup> About distributive tools in medicine see Annemarie Mol's discussion on indication criteria in the surgical treatment of atherosclerosis (Mol 2002a: 96–102).

<sup>54</sup> Fieldwork notes, Suzuran Hospital, August 28, 2003.

<sup>55</sup> Fieldwork notes, Suzuran Hospital, February 22, 2004.

<sup>56</sup> Fieldwork notes, Suzuran Hospital, February 27, 2004.

<sup>57</sup> *Ibid*

<sup>58</sup> *Ibid*

<sup>59</sup> Fieldwork notes, Suzuran Hospital, October 2, 2003.

<sup>60</sup> Twenty years ago Laura Nader was writing about the lack of work connecting these related research interests (Gonzalez et al. 1995), but it is fair to say that the situation has considerably changed since then as I have indicated in the introductory review of this thesis.

<sup>61</sup> Christiane Sinding offers a Fleckian reading of the formation of what she calls 'metabolic thought style' among endocrinologists after the discovery of insulin during the late 1920s (Sinding 2004).

<sup>62</sup> Classic examples include organ transplantation which is claimed to be at odds with Buddhist and/or indigenous animistic ideas of life and death in Japan (e.g. Lock 2002; Namihira 1988), and contraceptive pills which used to be prescribed only for 'medical problems' providing a fertile ground for a feminist critique of Japanese health policy (Ashino 1999).

<sup>63</sup> In 2004, there were 53,209 different kinds of medical devices approved for the Japanese market worth 1.9 trillion yen (JAAME 2004). The pharmaceutical market, in 2006, included approximately 29,000 products (12,000 OTC and 17,000 ethical drugs) and accounted for about 6 trillion yen (Drugs in Japan Forum 2006). (OECD 2005) provides a comparative statistical overview of the diffusion of medical technologies (46-47).



<sup>64</sup> For more recent statistics on the diffusion and assessment of medical technologies in Japan, see the homepage of the Ministry of Health, Labour and Welfare (MHLW) for the updates of the nationwide survey (MHLW 2017); for international comparison, see (OECD 2015: 101). As of 2015, Japan continues to be the country with the highest number of paradigmatic medical devices, such as CT scans and MRI, per capita among the OECD countries (OECD 2005: 99).

<sup>65</sup> The sociologist Tateiwa Shinya's work, that tries to capture the interaction between personal and social problems of keeping people with neurodegenerative disorder alive on artificial respirators, is an important exception in this regard (Tateiwa 2004). On the social context of paradigmatic medical technologies in Japan, see Margaret Lock (2002) and Yamazaki Gorō (2015) on organ transplantation, Tsuge Azumi (1999) on reproductive technologies, Nudeshima Jirō (2001) on genetics and Suzuki Wakana (2018) on stem cell research.

<sup>66</sup> For an introduction to the social constructivist approach to medical technologies see e.g. (Elston 1997); for a Japanese overview, see (Matsubara 2002).

<sup>67</sup> For different versions of technological determinism see (Reiser and Anbar 1984) and (Uesugi 2001).

<sup>68</sup> Medical artifacts and technologies occupy an increasingly important place in the dialogue between the sociology of science and technology, medical anthropological and empirical philosophy (Cambrosio et al. 2000a; Edwards et al. 2010; Vos and Willems 2000). Building on the long-standing anthropological tradition of exploring the lived relations between cultural actors, meanings and objects (Evans-Pritchard 1937; Kopytoff 1986; Mauss 1950 [1925]), these studies show how technological innovations, scientific discourses and suffering selves affect each other in contemporary biomedicine. For detailed ethnographies of medical devices and instruments see e.g., (Dumit 2004) on PET scanning, (Pols 2012) telecare and (Thompson 2005) on reproductive technologies; on pharmaceuticals see e.g. (Lakoff 2005), (Gomart 2002); for a historical overview, see (Yamanaka 2009); for literature reviews see (Sobo 2005) and (Lock 2004).

<sup>69</sup> Interview with private practitioner, Tokyo, March, 2005.

<sup>70</sup> Hypoglycemia is the abnormally low level of sugar in the blood (less than 70mg/dl according to the Japanese standard) caused almost exclusively by insulin injection and some other diabetes treatments as a side effect or a result of bad control. It causes dizziness, fatigue, sweating, etc. and may lead to panic and even coma.

<sup>71</sup> The argument of this chapter owes much to the works of Annemarie Mol and Charis Thompson (Mol 2002a; Thompson 2005).

<sup>72</sup> On the evocative role of translation in ethnographic theory, see (Morita and Mohácsi 2013); for a more specific discussion of the translations of Western concepts into Japanese anthropology, see (Jensen and Morita 2017).

<sup>73</sup> Classic material-semiotic approaches to the interaction of human and non-human actors usually fail to explain this embodied dimension of using technologies. While these authors, too, claim to focus on technologies in practice, their focus is on how meanings from signs are configured (e.g. Woolgar 1991) or inscribed (e.g. Akrich 1992) to technological objects. Haraway's figure of the cyborg (1985) is probably closer to what the Japanese language refers to as *mi ni tsukeru*, but here, in my opinion, the relations between humans and machines are rarely treated as practicalities in the strict sense of the word. For more on the possibilities of bringing phenomenological and STS approaches closer, see the special issue *Bodies on Trial* published in the journal *Body & Society* (Berg and Akrich 2004)

<sup>74</sup> Fieldwork notes, Shitamachi Clinic, July 17, 2004.

<sup>75</sup> In routine annual screening, however, the more simple fasting plasma glucose (FPG) test was recommended to identify undiagnosed cases of diabetes. For a primary source on the Japanese parameters and categories of hyperglycemia see 『糖尿病診療マニュアル 2003』 [Treatment Manual for Diabetes 2003] (Murase 2003: S36); for the most recent edition, see 『糖尿病診療ガイドライン 2016』 [Guideline for the Treatment of Diabetes, 2016] (Japanese Diabetes Association 2016).

<sup>76</sup> Interview with physician, Suzuran Hospital, August 21, 2003.

<sup>77</sup> Fieldwork notes, Suzuran Hospital, February 3, 2004.

<sup>78</sup> *Ibid.*

<sup>79</sup> Fieldwork notes, Suzuran Hospital, October 1, 2003.

<sup>80</sup> Interview with Tamura-san, Suzuran Hospital, September 11, 2003.

<sup>81</sup> Fieldwork notes, Suzuran Hospital, September 9, 2003.

<sup>82</sup> Melanie Rock makes a similar point in her study of the politics of diabetes in Canada: "(...) the diagnostic criteria for diabetes presume the capacity for secondary prevention; that is, the capacity to avert or delay physical complications in people with diabetes. In adopting these diagnostic criteria, physicians and diabetes organizations imply that people need to be equipped—personally, socially, and materially—to exert influence over their own futures." (Rock 2003: 151)

<sup>83</sup> For an STS-minded history of imaging technologies in medicine, see (Blume 1992). In addition, (Barley 1988) is an insightful early ethnography of how visual technologies shape modern biomedicine in the hospital.

<sup>84</sup> While not rejecting the important epistemic shifts of medical images stressed by feminist scholars and anthropologists (Martin 1992; Rapp 1999), and the ontological weight of visual representations in the production of scientific proof (Latour 1990; Lynch 1988), here my focus is on the practicalities of appropriating and embodying such medical images of disorder.

<sup>85</sup> Fieldwork notes, Suzuran Hospital, February 4, 2004.

<sup>86</sup> Fieldwork notes, Suzuran Hospital, February 9, 2004.

<sup>87</sup> Fieldwork notes, Suzuran Hospital, Feb 17, 2004.

<sup>88</sup> *Ibid.*

<sup>89</sup> On the use of onomatopoeia in a laboratory setting in Japan, see (Suzuki 2015).

<sup>90</sup> Fieldwork notes, Suzuran Hospital, Feb 17, 2004.

<sup>91</sup> Medical anthropologist, Hoshino Shun investigates this shift toward ethical choices in Japanese medical settings on the example blood transfusion refusal by Jehova's Witnesses (Hoshino 2002). In the context of pharmaceuticals, see Adam Hedgecoe's discussion of personalized medicine (Hedgecoe 2004).

<sup>92</sup> Fieldwork notes, Suzuran Hospital, August 25, 2003.

<sup>93</sup> About hypoglycemia, see note 70 above.

<sup>94</sup> I will return to a discussion of this productive and ethical relationship between diabetes and the Japanese pharmaceutical industry in Chapter 5.

<sup>95</sup> Fieldwork notes, Suzuran Hospital, July 21, 2003.

<sup>96</sup> In the original: 「薬物療法を始めても、食事療法や運動療法が実践されていないと、よい結果が得られない。この点が、同じ生活習慣病でも薬物療法が主体となっている高血圧や高脂血症と異なる点である。糖尿病でも経口血糖降下薬やインスリンの種類が増えたり、併用療法が一般的になるなど、薬物療法が強力になっているが、食事や運動という生活習慣の自己管理への依存度が高い特徴である。」

<sup>97</sup> Fieldwork notes, Shitamachi Clinic, June 14, 2004.

<sup>98</sup> Interview with Katori-san, June 22, 2004.

<sup>99</sup> Fieldwork notes, Suzuran Hospital, September 19, 2003.

<sup>100</sup> *Ibid.*

<sup>101</sup> See (Hattori In press) for a related argument in the context of pain management and the use of methadone and morphine in palliative care.

<sup>102</sup> I am grateful to Casper Bruun Jensen for this valuable suggestion.

<sup>103</sup> At other levels, of course, the same machines may reduce difference (e.g., fat becomes a standard risk factor of complications). These levels, however, exist simultaneously and in junctions. They are in contrast without being exclusive.

<sup>104</sup> For an excellent case study of this process of translation in biomedical research and the emergence of care as a scientific practice, see (Frieze 2013).

<sup>105</sup> BioBank Japan is a DNA repository—mostly for chronic conditions—established during the period of my research. I will discuss it in more detail in Chapter 5.

<sup>106</sup> For clinical studies of evaluating self-management programs of and lifestyles in chronic conditions, see (Bramson 1996) on asthma and (Kennedy et al. 2013) in general. On diabetes trials, see (Takata et al. 2002) for Japan, (Trento et al. 2010) for Italy and (Vos et al. 2016) for Sri Lanka, among many others. Last, but not least, Dick Willems (2000) provides an insightful philosophical interpretation of the issue.

<sup>107</sup> The study of translational medicine and clinical trials has emerged as a central focus of interest across medical anthropology and science studies during the past decade including important works by Steven Epstein on the consequences of the AIDS epidemic (1996) and differentialist clinical medicine in the U.S. (2007), Peter Keating and Alberto Cambrosio (2003; 2011), on cancer studies in France and North America Kuo Wen-Hua (2005) on the regulation of clinical research in Taiwan and Japan, Adriana Petryna (2009) on the outsourcing of clinical trials in Eastern Europe, Wenzel Geissler and Catherine Molyneux (2011) on Africa as an experimental site of pharmaceutical innovation, Charlotte Brives (2013; 2016) on the alignment of patients and researchers in clinical trials in Burkina Faso and Kaushik Sunder Rajan (2017) on the co-production of pharmaceuticals and democracy in India, to name just a few. For more case studies, see the chapters in the edited collection, *Medical Proofs, Social Experiments: Clinical Trials in Shifting Contexts* (Will and Moreira 2010).

<sup>108</sup> On the history of diabetes clinical trials, see (Marks 1997); Melanie Rock (2005b) provides an anthropological account on the effects of evidence-based medicine in diabetes care.

<sup>109</sup> For an excellent description of these two thought collectives of the so-called 'disciplinarians' and 'liberals,' see Christiane Sinding's Fleckian account (Sinding 2004).

<sup>110</sup> Interview with Dr. Tanabe, Hospital T., March 16<sup>th</sup> 2005.

<sup>111</sup> *Ibid.*

<sup>112</sup> This is, of course, not necessarily true for pharmaceutical trials where drugs are tested first on healthy people. On the difficulties of recruiting healthy subjects see Steven Epstein's account on "recruitmentology" in Chapter 9 of his monograph (Epstein 2007). For a more specific discussion of the problem of recruitment for cancer trials in the U.K., see (Faulkner 2010).

<sup>113</sup> This situation has changed with the ongoing health care reform discussed below. Starting from April 2008, a new annual health check-up scheme was introduced to examine all Japanese citizens aged 40-74 on the expense of public health insurance associations.

<sup>114</sup> Interview with Dr. Nazono, Suzuran Hospital, July 20, 2005.

<sup>115</sup> For more on the figure of the *sararīman* and its transformation in the social imagery, see (Dasgupta 2013; Taga 2017).

<sup>116</sup> Dr. Nazono was referring to the so-called National Diabetes Survey, a report on the actual condition of diabetes in Japan published by the Ministry of Health, Labor and Welfare every five years (厚生労働省 2004).

<sup>117</sup> For a similar case, see Harris Solomon's ethnography of metabolic illnesses in Mumbai. As he pointed out, in India, the main target of public health intervention and media frenzy around obesity and diabetes during the 2000s were young office workers, who "were too busy to feed, thus care for, themselves" (Solomon 2016: 53).

<sup>118</sup> During the prosperous years of economic growth between the 1960s and 1990s, the *sararīman* (literally, wage-earner; or corporate employee, in a narrower sense) represented the new lifestyle of the young, urban middle-class. Arguably, it is exactly this age-cohort that later suffered from chronic conditions, called lifestyle-related diseases (*seikatsu shūkan byō*) during the long years of recession since the mid-1990s.

<sup>119</sup> Fieldwork notes, Suzuran Hospital, July 11, 2004.

<sup>120</sup> For a detailed account of the health care reforms in English, see Chapter 2 in (Olivares-Tirado and Tamiya 2014); for a critical review in Japanese, see (Ōmori 2014).

<sup>121</sup> In the original: 「メタボリックシンドロームの件でも明らかになりましたように、エビデンスとはとても言えないようなものをエビデンス、エビデンス、エビデンスというふうにいって、国の出す医療費を削減して国民に負担を強いるというところでもない改革案だということでございます。」 (第22 回厚生科学審議会地域保健健康増進栄養部会 資料 (資料4) . 医療制度改革法案の国会における審議状況 (平成18 年6 月13 日))

<sup>122</sup> See Harris Solomon's discussion of this debate from an Indian perspective in Chapter 1 of his book, *Metabolic Living* (2016).

<sup>123</sup> For an updated version of the concept, see (Nading 2017).

<sup>124</sup> There is an increasing amount of work on the genetics of disease in both science studies and anthropology addressing the intersection of research practices and the classification of disease (Hedgecoe 2002), drug promotion (Montoya 2011) or public health issues (Rock 2005c).

<sup>125</sup> The former shows a Mendelian pattern of inheritance, therefore they are often referred to as monogenetic or Mendelian disorders in the medical literature. Complex diseases, diabetes among them, are labeled as polygenetic or multifactorial by geneticists. There are, however, rare forms of diabetes that can be related to the defect of one single gene, e.g. MODY (mature onset diabetes of the young).

<sup>126</sup> For an overview of the anthropology of genetics and race, see (Abu Ei-Haj 2007); for an STS-oriented introduction to the production and reception of genomic knowledge, see (Hedgecoe and Martin 2008). Social scientists have been following the development of the biotechnology industry in Japan. For two different approaches, see the historical account of technological change in (Collins 2004) and the sociological explorations of ethical issues in Tsuge and Kato 2007; Hara Takuji's (Hara 2003) economic case studies of pharmaceutical innovation are also strongly influenced by science studies.

<sup>127</sup> Sheila Jasanoff's (2005) comparative analysis of American, British, and German political responses to biotechnological innovations is rich in theoretical insights. For more specific case studies with a focus on biobanks, see (Gottweis and Petersen 2008).

<sup>128</sup> For a dense exploration into the place of comparison in Strathern's work, see (Holbraad and Pedersen 2009).

<sup>129</sup> The event was *I to Genomu* ("Medicine and Genome"), the third symposium of the Japanese Association of Medical Sciences, Sapporo Prince Hotel, 6–7 September 2001.

<sup>130</sup> In the original: 「日本人の糖尿病の遺伝素因・分子病態の解明とオーダーメイド治療」第3回日本医学会特別シンポジウム：人とゲノム，札幌プリンスホテル国際館パミール，2001年9月.

<sup>131</sup> The plural, of course, would be more appropriate here—*genes* rather than *gene*—but this is more than ambiguous in the Japanese language.

<sup>132</sup> Much has been written on the thrifty gene. On the expansion and transformation of the concept in epidemiology, see, for example, (Hales and Barker 1992) and (Zimmet 2000). For an excellent anthropological overview, see (Paradies et al. 2007), and also (Ritenbaugh and Goodby 1989) from a biological anthropology perspective. Its ethical implications have been discussed by (McDermott 1998), among others. For a Japanese introduction of the concept, see (Tsuda 2003).

<sup>133</sup> It is worth emphasizing, however, that these facts, in the Japanese context, are only very rarely categorized in terms of race—a central issue in Montoya's analysis. The few exceptions are likely to be publications for specific international journals or pharmaceutical research with targets that are also valuable candidates for the North American market.

<sup>134</sup> Lodish laboratory (Massachusetts Institute of Technology); Spiegelman laboratory (Harvard University); Osaka University, and Showa University.

<sup>135</sup> *Nemawashi* means to "lay the groundwork [for obtaining one's objective]; maneuver behind-the-scenes" (*Kenkyusha's New Japanese-English Dictionary*, 5th ed., 2003).

<sup>136</sup> The genetic research of complex diseases is a case in point in the lively debates around emerging biosocial formations and historical impetus of the life sciences (Rabinow 1999; Rose 2007). For case studies, see (Fujimura 1996) on cancer, (Lakoff 2005) on bipolar disorder in Argentina, (Lock et al. 2007) on Alzheimer's disease in North America, and (Pálsson 2004) on osteoarthritis (joint disease) in Iceland.

<sup>137</sup> Adam Hedgecoe (2004) described this emerging field extensively from a sociological perspective. He writes: "In 1997 a new word appeared in the literature, 'pharmacogenomics', the meaning of which was less clear than in the case of pharmacogenetics, with competing definitions of the term vying for recognition. Recently there has been a move towards a consensus on the differences between the two terms, coming into line behind the idea that pharmacogenetics is about testing individuals for drug response, whereas pharmacogenomics is used more broadly to describe the 'the concept of using whole-genome information to predict drug action' (Roden and George 2002: 37). As Roche's Klaus Lindpaintner puts it, pharmacogenetics is about 'one drug, many genomes' while pharmacogenomics, with a focus on how the same genome may vary its expression in the face of a variety of different products, concerns 'many drugs, one genome'" (Lindpaintner 2003: 317–318; cited in Hedgecoe 2004: 4).

<sup>138</sup> The first so-called ethnic drug that was approved on the basis of pharmacogenomic findings in the United States was BiDil, prescribed for heart failure in African American patients (Inda 2014; Kahn 2008). There are other less successful attempts to tune medications to genetic variation; for an insightful account from the field of psychiatry, see (Lakoff 2005). See also (Ninnemann 2012) on the pharmacogenomic understanding of traditional medical knowledge in the case of mental disorders.

<sup>139</sup> The cutoff between mutations and polymorphisms is generally considered to be 1 percent.

<sup>140</sup> In the original: 「Q: 民間にも情報提供するそうですが、それは具体的にはどういうところに情報を提供するのですか？もし製薬会社などに情報提供するならその企業だけに利益が行ってしまうように思われるのですがそうとは限らないのですか？A: 製薬企業や診断企業への提供を行います。もしこれらの企業が利益を得ることになれば、それは新しい薬や新しい診断法が開発されたことを意味し、患者さんにも大きな利益をもたらすことを意味します。また利益を得た企業は税金を納めるという形で国に貢献することにもなります。」

<sup>141</sup> A 2004 article in the magazine *Nikkei Baiobijunesu*, for instance, reported on his work on adiponectin in a special issue on the potential fields of cooperation between science and business in biomedicine: "Adiponectin, which is secreted from fat tissue, stimulates the oxidation of fatty acids in the liver and muscle. It also appears to have a suppressive effect on the progression of atherosclerosis. It is a hormone that developed countries that struggle with a growing population of obese people need like a shower in the desert. [Kasahara] puts forward four ways to apply the results of his findings in developing new medications [noting that] they all start from the collaboration between industry and university. (...) The promise that one single biological agent may be related to different tissue-selective patterns will have strong implications for drug discovery attracting considerable attention" (Nikkei Biobusiness 2004: 106).

<sup>142</sup> A series of failures of new blockbuster pharmaceuticals to reach broad segments of the population, and the expiration of patents due to the increasing length of clinical trials created a sense of crisis at the beginning of the millennium in the pharmaceutical industry worldwide. A further impetus for change came from the emergence of unpatented and state-supported drug manufacturing in third-world countries and, in Japan, the increasing presence of foreign companies in the domestic market. The growing share of over-the-counter and generic medications, and their active support by the Japanese government, gave way to the fragmentation of this market, creating a new context of drug development abroad and at home as well.

<sup>143</sup> Note that adiponectin had not even been discovered at this point, so the mechanism of glitazones was explained without much of our current knowledge about this hormone.

<sup>144</sup> "PROactive" stands for "PROspective PioglitAzone Clinical Trial In MacroVascular Events."

<sup>145</sup> It is into this fray that Kasahara has chosen to launch by taking the position of a project leader in the largest study of its kind, the Japan Diabetes Outcome Intervention Trial, which started in 2005.

<sup>146</sup> For further case studies about the effects of pharmaceutical marketing on the cultures of medical care in Ghana, India and the United States, see (Hamada 2015; especially Chapter 2) (Ecks 2014), (Sunder Rajan 2017), and (Dumit 2012)

<sup>147</sup> This position is perhaps not so far from that of Lakoff, who, a few pages later in the same book, turns the former claim into an open-ended question: "If sciences such as epidemiology emerged in the context of regulating the health of collectivities within a territory, how should we understand new forms of knowledge such as audit data with respect to the problem of government?" (2005).

<sup>148</sup> The concept of *commensuration* employed in this chapter partly follows the sociological definition of Wendy Nelson Espeland and Mitchell L. Stevens who wrote in their review article: "Commensuration is the expression or measurement of characteristics normally represented by different units according to a common metric. (...) [it] transforms qualities into quantities, difference into magnitude. It is a way to reduce and simplify disparate information into numbers that can easily be compared. This transformation allows people to quickly grasp, represent, and compare differences" (1998: 315–316). However, where their argument rests on the assumption that commensuration is a feature of social life that is *more than* mere technical processes, the qualifier "technosocial" in front of the term in this thesis is meant to highlight the co-constitution of these two realms in the very practices of commensuration.

<sup>149</sup> See (Callon and Rabearisoa 2008; Rabearisoa 2006) for a discussion of the engagement of lay people in medical research in Europe.

<sup>150</sup> For an english overview of the role of water in the history of urban Tokyo, see (Jinnai 1995; especially pp.100–107 on the development of Shitamachi). For ethnographic portraits of daily life in this part of Tokyo in English, see (Bestor 1989; Kondo 1990).

<sup>151</sup> Fieldwork notes, Public Health Center, Koto Ward, October 12, 2005.

<sup>152</sup> Fieldwork notes, Public Health Center, Koto Ward, October 27, 2005.

<sup>153</sup> For a medical anthropological approach to community health, see Suzanne Schneider's ethnography of Mexican grassroots health promotion. She note: "As states weaken and public health care deteriorates throughout the developing world, new spaces are opening for civil society groups to fill the gaps of declining health systems. In Mexico, popular health groups have responded to health care decline by building community clinics, establishing health promoter training programs, and opening natural medicine pharmacies" (Schneider 2009: 235).

<sup>154</sup> Fieldwork notes, Public Health Center, Koto Ward, December 2, 2005.

<sup>155</sup> *Ibid.*

<sup>156</sup> For a critical, Foucauldian take on the politics of social control and Japanese public health, see (Borovoy 2017).

<sup>157</sup> Fieldwork notes, Murata-san's home in Sunamachi, Tokyo, December 20, 2006.

<sup>158</sup> Fieldwork notes, coffee shop in Kameido, Tokyo, February 1, 2007.

<sup>159</sup> *Ibid.*

<sup>160</sup> Fieldwork notes, Murata-san's home in Sunamachi, Tokyo, June 3rd, 2006.

<sup>161</sup> For a thorough ethnographic account of how nutrition becomes a personal narrative and a reputable science at the same time and in concert with each other in health advocacy in Guatemala, see (Yates-Doerr 2015).

<sup>162</sup> Fieldwork notes, Murata-san's home in Sunamachi, Tokyo, April 1, 2006.

<sup>163</sup> On the notion of *dispositif* see (Foucault 1980); (Nakagawa 2009).

<sup>164</sup> On the enactment of ideals in medicine, see (Mol 2008b; Pols 2004).

<sup>165</sup> Fieldwork notes, Kinshichō Park, Kōtō Ward, Tokyo, April 5, 2006.

<sup>166</sup> On the first wave of epidemiological studies of population health and chronic disease, see the widely cited article by Geoffrey Rose (1985) who forcefully argued for the separation of incidence and incidents in order to shift the attention from individual determinants of health to population risk.

<sup>167</sup> It seems close to impossible to align them with each other with the available conceptual tools of medical anthropology, although there are considerable attempts both in and around the discipline. See e.g. (Glabau 2016) on food allergies or (Whitmarsh 2008) on asthma. It has also been repeatedly argued that the chronicity of these conditions is deeply intertwined with their respective regimens and the existential confrontations that stem from such situations (see e.g. Charmaz 1991).

<sup>168</sup> In the original: 「学校では教師も生徒と一緒に給食をとるんですね。でも、給食というのは生徒たちに合わせて作られていますから、高血糖の私にはカロリーが高すぎるんです。といって立場上残せませんね。それでなんとか昼食以外のほかのところでカバーするよう努力していたんです」。

<sup>169</sup> In the original: 「ほとんど変わらず (...) ショックでしたね。こんなに努力しているのになぜだ！って感じで (笑) 。」

<sup>170</sup> In the original: 「驚くほどよくなったんです。今、血糖値はまったく問題ありません (….) ストレスも不思議なくらい無くなりましたね。コレステロールも体脂肪も問題無くなりました。」

<sup>171</sup> In this sense, this thesis contributes to the growing literature on the emergence of chronicity since the second half of the 20th century that includes important historical (Weisz 2014), anthropological (Manderson and Smith-Morris 2010) and sociological (Charmaz 1991) interpretations.

<sup>172</sup> Thai peasants become skilled at assembling and repairing agricultural machines under the umbrella of so social networks emerging around local factories (Morita 2007). Or take, for example, the parents of disabled children in France who formed patient groups to study the drugs and technical facilities required for their children's treatment. They not only contribute to, but actively participate in clinical trials of muscular dystrophy (Rabeharisoa and Callon 1999).

<sup>173</sup> Carrie Friese, for instance, argues in her recent ethnography of cardiovascular disease in animals that care is implicit in the "experimental system" (Friese 2013: S137). She describes how researchers working with mice and other model animals increasingly became aware of the difference that enhanced husbandry could make in the scientific output of their experiments. In her case study, pharmacologists in a British laboratory implanted a specific telemetric device into the body of the mouse to reduce the stressful interventions of physical and cognitive data collection at later stages of the research. That strategy illuminates how caring for experimental animals is an ethical-methodological foundation—rather than an altruistic act of animal welfare—on which the comparability of the experiment comes to depend. By transforming the body of the model organism, "care creates trajectories that potentialize animals as better models for humans. A cultural understanding of animals as fleshy and fragile shapes their biological development within science and the corresponding biological knowledge that is produced" (136). In a similar fashion, it is the switching of scales between particular sites of knowledge practices that make explicit the links between metabolic and cultural differences in the present study.

<sup>174</sup> Social theorists have been updating this largely neglected concept in recent years by coining the term "metabolic rift" to describe the interaction between humanity and nature as it has been transformed through labor (Foster 1999; Moore 2011).



<sup>175</sup> In *From the Enemy's Point of View*, Viveiros de Castro writes: "The virtue of enemies that was necessary to incorporate was precisely that of being enemies: this is what was eaten. Instead of a "magical superiority" obtained by the dissolution of the enemy's identity in the belly of the society of eaters, such a superiority would be derived from a determination by the enemy, a cannibal transformation into the enemy. The contrary of an identification—literally, an identification to the contrary. (...) This hypothesis is consistent with what we have seen among the Araweté: there, too, the killer becomes an enemy, and this makes him become immortal. I also suggested that the inexhaustible vigor of the Maï perhaps due to this anthropophagous ambrosia. Likewise, Tupinamba cannibalism was an incorporation of enmity that sought immortality—for the eaters and for the eaten" (Viveiros de Castro 1992 [1986]: 286).

<sup>176</sup> Clearly, this is an overtly simplistic summary of Amerindian perspectivism. For a general overview, see (Fausto 2007). Fausto distinguishes at least two versions of perspectivism. Cannibalism, on the one hand is eating the other as person, which establishes a dangerous vector of potentially reversible modification—one can be captured by one's prey; predation, on the contrary, is eating the other as food, which in turn enables commensality with other fellow persons, shared kin.

<sup>177</sup> A bride's kin, for example, eat her bride wealth at the marriage thereby decomposing their kinship ties: "The mother's pig [*mam peng kng*] is given in explicit recognition of the loss of her daughter at marriage (...) The pig destined for the mother is handed over live. A crucial point at which she eats, and from which she (conventionally) derives pleasure, is when she receives it. The pleasure is not just in anticipation of meals to follow. It is, we might say, her person (an object of the regard of others) who is seen (by others) to be the eater; as a recipient, she herself eats as an agent of others' giving/feeding. In eating the outcome of their work, she also eats their acknowledgement of hers. (...) The groom's mother grows the pig by feeding it; her husband and his close kin will, in giving it to the bride's side, mark its destination for the bride's mother, who has until now been feeding the bride. (...) What agents eat of others are the outcomes of those others' actions, the things they have grown and nurtured. What is consumed is not the capacity to grow and nurture, but that capacity as it was converted by their acts into the bodies of people, plants, animals" (ibid: 7–8, 11).

<sup>178</sup> For another, ecological, example, see the work of Filippo Bertoni (2016) who followed the experimental work of soil scientists in the Netherlands. These experiments, as Bertoni demonstrates, fold the metabolic activity of earthworms into the future of the planet through the transformation of Dutch grasslands.

<sup>179</sup> Inspired by Filippo Bertoni's notion of the ecological version of togetherness (2016: 14).

<sup>180</sup> For a different take on how living with diabetes constitutes metabolic commonality, see (Ferzacca n.d.)

<sup>181</sup> For a historical account on this kind of pharmaceutical mediation between theories and lay experience in diabetology, see (Greene 2007: 83–115).

<sup>182</sup> I owe this little story Kimura Yumi who, unfortunately, could not help the mother, but was inspired to continue her research about the consequences of lifestyle disease (*seikatsu shūkanbyō*) on the lives of the Dani people in New Guinea.

<sup>183</sup> For detailed accounts of Strathern's notion of postpluralism, see (Holbraad and Pedersen 2017: 130–140; Jensen and Winthereik 2013: 141–144).

<sup>184</sup> But see Matei Candea's warning against too much expectations from relationality: "the very same encounter which can open up a space for relationality in this way can also become a vector of schismogenesis, when people use the notion of cultural difference as a frame through which to read and objectify each other's behavioral proprieties" (Candea 2010: 173).

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