TREATABILITY

Sociomaterial configurations of hearing loss and diabetes

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Sociomaterial configurations of hearing loss and diabetes

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PhD Dissertation

University of Southern Denmark

ANONYMITY AND CONSENT

All research participants in this thesis are anonymized and the names I use are pseudonyms. Photos have been modified for confidentiality. Anyone who provided personally sensitive information, including health information signed a consent form prior to the recording of interviews and clinical interactions (in accordance with the rules of the Danish Data Protection Agency).

MANUSCRIPT FOR PHD DISSERTATION

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CONTENTS

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CHAPTER ONE

INTRODUCTION

This thesis is an ethnographic study of how doctors and patients deal with diabetes and hearing impairment, and how they relate to particular treatment devices. Both conditions are commonly considered treatable because they can be aided with modern treatment technologies; the hearing loss with a hearing aid and diabetes with insulin injections amongst other treatments. In this work, I bracket the common understanding of 'treatable', in favour of an empirical investigation of how diabetes and hearing loss are made relevant to treatment in situated everyday practices. I do so through an ethnographic investigation of how doctors and patients examine and handle the two conditions in clinical encounters, and how patients deal with the conditions at home in ways that make them relevant, or not, to treatment.

My engagement with these issues has emerged from my involvement in the research project 'Innovating with pre-users of medical devices'. The project was initiated in 2009 in collaboration between two Danish medical device manufacturers, Novo Nordisk and Oticon, and the SPIRE Research Centre at the University of Southern Denmark. The two companies shared an interest in the apparent paradox that people with a chronic medical condition delay starting to use treatment technologies until well past the point at which they could benefit from them. Novo Nordisk wanted to understand what keeps people with poorly regulated type 2 diabetes from using insulin injection devices. Oticon was interested in unearthing what keeps adults with acquired hearing loss from using hearing aids. Both conditions are chronic and incurable, but can be managed with technological treatment devices. Left untreated, both hearing loss and diabetes can have severe consequences. Hearing impairment prevents people from taking part in conversations and possibly leads to social isolation (Christensen 2006). It may also cause early retirement from the workforce, and more recently it has been associated with dementia (Lin et al. 2011). Type 2 diabetes may remain undetected for years, but can cause severe illness and death. It may damage the blood vessels, nerves and connective tissues, and late complications include blindness, amputations, kidney failure and cardiovascular events (Danish College of General Practitioners 2012; International Diabetes Federation 2013). Even so, in the United States of America, only 1 in 5 of people with hearing loss own a hearing aid, while only 1 in 2 people with diabetes are in medical treatment[1] (Centre for Disease and Control Prevention 2011; National Institute of Deafness and Other Communication Disorders 2010). My role in the project was to study 'the barriers that inhibit pre-users from becoming users of medical treatment devices'[2]. Both companies wished to expedite technological intervention, and I was asked what causes potential users to delay starting treatment.

During my 10 months of fieldwork in Denmark and the United States of America, I visited medical clinics, observing doctors and patients as they discussed the conditions and worked out treatment plans. I also visited people with hearing loss or diabetes in their homes to understand how they dealt with their conditions in everyday life. However this thesis does not reveal the apparent paradox about the late onset of use. It does something else. It takes the assumption that the two health conditions are in need of treatment and makes it an empirical question; how is the relevance of treatment accomplished in particular circumstances? As I started my ethnographic research, it soon appeared to me that people who were living with hearing loss or diabetes did not always see the treatment devices as future solutions to the problems they were faced with. Sometimes a person managed his or her hearing loss by sitting close to the source of the sound, leaning forward or asking other people to repeat themselves. The problem of diabetes was not confined to excessively high blood sugar values but also involved transforming an abstract future risk of falling sick without allowing it to colonialize everyday life. People applied a variety of solutions, and their future horizons were rarely about becoming users, but more often about avoiding it. I therefore resolved to explore how the conditions emerged as problematic to the people who were living with them, and how they related to available treatments.

As I was moving between clinics, homes and disease areas, what at first seemed to be obvious practices for measuring, knowing and treating hearing loss and diabetes, soon appear rather peculiar in comparison. In the original framing of the project, I was asked to conduct two parallel

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[1] Of the people with diabetes in 2011, 63% were diagnosed and of these 84% was in some medical treatment (Centre for Disease and Control Prevention 2011).

[2] The quote is from the original research plan, as it was formulated in collaboration between the companies and the SPIRE.

studies of hearing impairment and diabetes. I decided to turn this parallelism into an analytical strategy that runs through my thesis and by virtue of the contrasts between practices of handling hearing impairment and diabetes particularities of each practice are rendered more visible.

Treatable health conditions

From an anthropological perspective, the project framework posed several interesting challenges. It set the scene for a comparison between a potentially life-threatening but vaguely noticeable diabetes and the functional impairment caused by hearing loss. It also suggested that people with these conditions move along a trajectory from pre-use towards use; the companies often called this the ‘user journey’. What most intrigued me, however, was the assumption that we can understand human behaviour as the result of barriers to an otherwise rational or natural course of action. This assumption seemed to echo Boor's ‘sociology of error’, where the social is only taken into consideration when medical rationality fails to manifest itself (Timmermans and Berg 2003). In other words, social science is used to explain failures in rational behaviour. In the field of medical anthropology there is a consensus that the ‘medical model’, that sees modern medicine as a primarily diagnostic practice, which enables doctors to answer patients’ questions with true scientific knowledge and treatment plans, may describe how we picture medical practice, but does not reflect how people act when faced with suffering and illness (Good 1994). I share with Mattingly the understanding that patients and healers act in a realm of ‘diverse rationalities and multiple realities’, and that clinical practice is guided by a practical reasoning and understanding of what a good solution is in a particular case (Mattingly and Hunt 1998; Mattingly 1998). The issue is then how relations between diseases and their treatments emerge under specific circumstances, as locally situated phenomena and not as failure of some detached rational model. In this spirit, I move from a question about what keeps people from starting a medical treatment to a matter of how and when relations between bodies, diseases and treatments are enacted on particular occasions and with what consequences.

Hearing loss and diabetes are considered treatable because they can be aided with modern treatment technologies. This assumption underlies the question about barriers to treatment, and makes it possible to separate a factual and objectively known need for treatment from questions of relevance for social science about the reasons for not starting treatment. In this thesis, I reframe the question about treatable health conditions as an empirical anthropological investigation of embodied and situated practices in and through which a condition is rendered relevant to treatment. Rather than assuming a given relation between an ailment and a treatment, I explore this relation as it emerges through particular interactions. It may appear that I am questioning the benefit of treating these conditions. That is however, not the aim of my research. I am curious about *how* a disease is known to be treatable by the people who are living with it. With the term 'treatability' I turn my attention to the practices of relating to a condition as in need of treatment and I examine it as a practical accomplishment. In other words I reframe treatable, from a biomedical fact given as a resource for asking about the barriers to treatment, to an empirical consequence of concrete and embodied practice situated in particular circumstances.

From very early in the research project in 2009 to the end of 2011, I observed and recorded 74 doctor-patient interactions[3] in 12 clinics run by ear, nose and throat doctors[4] and general practitioners, and I visited 21 patients in their homes. The majority of the study was carried out in Denmark, while three months were dedicated to fieldwork in the country that makes up the largest market for both companies: the United States of America. From the central understanding that knowing and doing are inseparable, I set out to explore how the conditions were handled and found to be in need of treatment. The ambition was to bracket what we commonly take for granted about the relations between a disease located in the body, the treatment that may aid it and the subject facing the possibility of starting or delaying treatment.

ETHNOGRAPHIC CONTRASTS

My ethnographic material consists of diverse kinds of interaction between doctors and patients in the clinic, and myself, my informants and their family members; it is anchored by my analytical interest in the relations to the treatment devices. As I moved between sites, I noticed a variety of ways of handling hearing loss and diabetes. To give an impression of the practices of relating the medical conditions, the subject that may act upon it and the treatment that can be applied, let me describe some of the clinics and homes I visited.

The clinic

In a clinic near Copenhagen, a patient with type 2 diabetes sits across the table from his general practitioner. The patient has come for a routine check of his condition, and they are talking about how he is doing at home. The patient admits that he sometimes forgets his pills and complains that he feels tired a lot of the time. The doctor suggests that they should measure his blood sugar, and takes out a box with equipment. Without further instruction the patient places his forearm on the table, palm facing up. The doctor takes out a small device from the box and pricks the patient's finger while they continue to talk. The patient shows no sign of pain. With a little strip

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[3] I observed many more consultations, but only recorded those that fit the description of a pre-user (see chapter two on methods).

[4] In one case also an audiology clinic; see chapter two for details.

the doctor soaks up a few drops of blood and inserts the strip into the blood glucometer. A moment later he reads out a number from the display, comments that it is too high, and the patient promises to do better in taking care of his diabetes. In this instance, the disease is enacted in relations between the hand on the table, the blood on the strip, the meter, the doctor's reading of the number and the patient's promise to do better. The body as an object for medical practice emerges from the active and collaborative work of the doctor, who skilfully handles the needle, strip and measuring device, and the patient who puts his pain to service of clinical investigation. The subject position also emerges and changes over the course of interaction, as the patient moves from actively taking part in measuring, to being the body measured and finally being responsible for the result. The disease is not given prior to their interaction but emerges through practices of relating. The contingency of these enactments become even more visible as they are counterpointed with the practices of measuring hearing loss.

In another clinic just outside Copenhagen, another patient is having his hearing tested. A clinical assistant asks her patient to take a seat next to the audiometer[5]. The assistant carefully takes off his glasses, fits him with a set of earphones and instructs him to press the button in his hand every time he hears a sound. They now continue in silence; she operates the audiometer by pressing a button that allows her to move between discrete frequencies and a volume control to test the level at which her patient is able to hear the tone. He is looking into the distance with the small device in his hand, connected by a wire to the audiometer, pressing the button every now and then. The machine translates his reactions to little symbols and produces a curve that documents the threshold at which he is able to hear each tone. As the ear, nose and throat doctor returns to the consulting room, he asks his patient to look at the hearing curve on the computer screen with him. Two curves represent each ear's threshold of audibility, which is the level at which he is able to hear the tones they have tested. The doctor explains that the hearing is deteriorating, but adds that he must have 'big problems' with his hearing in order to feel like wearing a hearing aid. So he encourages his patient to go home and think about the extent to which he is bothered by his hearing loss. Like the first clinical encounter, the patient takes part in accomplishing the body as a measurable object, and the reading of the result is interpreted in relation to the patient's account. This time, it is not about how well the patient has treated his hearing. The patient states that he works as a blacksmith and does not use hearing protection, but that is not factored into the treatment plan. The patient's experience of his condition is, on the contrary, essential for the discussion of treatment.

The medical evidence is treated differently in the two instances. Where the blood sugar measuring is an evaluation of the body and the patient's efforts to manage his condition, the

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[5] A standard device used for evaluating hearing loss.

hearing curve becomes the basis for talking about problems that the patient has experienced. The authority and position of the patient also differs between the two encounters. The hearing impaired patient has epistemic authority to know his own sensation of hearing, and it is included in treatment plans. In the case of diabetes, the sensory experience of wellbeing is not taken as indication for a need for treatment by either doctor or patient. The subject positions emerge in the interactions between doctors, patients, devices and prospects of treatment, and are not pre-given to the situation. These situations did not reflect the 'medical model' in which conditions are revealed by a doctor through tests and physical examinations, resulting in a choice of treatment for the patient. Instead, I observed how conditions emerged through collaborative practices, where patients took part in producing the medical evidence and in the objectification of their body, and also engaged as subjects acting upon their disease, but with very varying epistemic authorities and space for action.

The home

Moving to the home and everyday life with the conditions led to another revealing displacement of the handling of the two conditions. Outside the clinic, hearing loss ceased to be a measurable capacity to hear discrete frequencies at certain decibel levels combined with a sensation of being troubled by the missing sounds. In the home it appeared when the flow of everyday activities and conversations was disrupted. People described not being able to move around in the same social space, but were confined to a smaller radius. Their problems were not always a matter of someone not-hearing. One informant told me, that he became aware of his hearing impairment when he left the indicator on in his car, and his wife had to tell him about it. Another informant told me how he never considered himself hard of hearing as he was working on building sites around loud machinery with men who had worked in the same kind of noise most of their lives and everybody was used to yelling. This changed when he became a manager and met with architects and administrators in quiet offices, where sounds were soft and at the same time important to hear. Yet another informant was no longer able to hear his wife from across their apartment, and observed that she would no longer talk to him from a distance. His wife, however, talked about repeating herself and feeling ignored. In some cases the hearing difficulties were skilfully counteracted by sitting closer to the person talking, in other cases they were pre-empted by avoiding difficult situations with many people. Hearing emerged as a relational matter and dealing with hearing loss involved negotiating, taking responsibility for moving closer, talking more loudly and paying attention. The impairment changed with situations, just as it changed the social space and relations within it.

Where hearing loss causes immediate problems that could be counteracted, diabetes may produce very few disruptions but poses an unpredictable future risk of complications. In the clinic, the practical concern was to evaluate the condition by measuring the blood sugar and trying to identify causes of peaks and drops in order to adjust the medication and modify the lifestyle. In the home people are faced with other concerns, and while measuring is part of living with diabetes, it achieves other goals than producing medical evidence. One informant carefully measured her blood sugar every day without making any adjustment to her medication. The measuring demanded patience, she explained, but also embodied the condition and reminded her of being a patient, for, as she told me, one of the dangers of diabetes is that it is easy to forget. Another informant was very concerned about not thinking of herself as a patient, and would hide all reminders of her disease. She channelled her concern for diabetes into a passion for healthy cooking. Another person I met had been running marathons and therefore ate what he wanted as long, as the doctor said his numbers were fine. Yet another patient used the quarterly measurements as goals for training and treating his diabetes, thus transforming the endless horizon of risk to a short-term objective. Practices of measuring and the medical evidence did much more than measure. In some cases they embodied and produced the condition as a constant reminder and thus an aid in controlling diabetes. For other people they created simplicity in relation to a condition that was otherwise difficult to understand and treat. Like hearing loss, diabetes is a relational condition that emerges in the situations where it is produced and treated.

The prospect of treatment

My movement between settings and diseases made it clear that these conditions are enacted in a myriad of ways. Being involved in a research project that focused on 'barriers to treatment', what caught my attention was how the prospect of technological treatment devices transformed the conditions with consequences for patients' capacity for acting and their moral rights and obligations. When doctors and patients discussed hearing aids or insulin as treatment of the conditions, certain features of the body, the subject and responsibilities were assembled in particular versions of the conditions, while other aspects would fade into the background.

A hearing aid is fitted in or behind the ear; it is barely visible and it enhances surrounding sounds and guides them into the ear canal. It figures hearing as a physical and sensory impairment to be solved on the body of the impaired person. While the advanced technology of the hearing aid enhances sounds, its low-tech requirements of putting the aid on every day and not forgetting it in a drawer, made doctors tell their patients that they needed to have 'big problems' and be ready to make the hearing aid 'a part of you' before using it. At home, family members would often encourage the hearing impaired person to ‘get something’ and one informant told me how he expected to ‘be at the gun for responding to everything’ his wife said if he got hearing aids.

The prospect of having to take insulin will bring some aspects of diabetes to the foreground. Most of the people with diabetes I met were undergoing medical treatment, so the prospect of insulin was not equated with a new diagnosis in the way that hearing aids were. Instead, it was related to a transformation of the condition. Insulin was the last resort, taken when other options failed to control blood sugar. Often the progression of the condition was marked by the treatment people received; as one person in the health centre told me, ‘I have a different kind of diabetes, because I take insulin’. The stage before insulin was often described as a reversible stage, where exercise and change of diet alone could manage the condition. Insulin represented a point where changing lifestyle was too late, and thus came to figure a condition that has progressed, because the patient had failed to treat the condition effectively.

From my fieldwork across these different sites, I came to see how the problems of diabetes and hearing loss emerged as multiply distributed practices. There was not a singular disease problem relating to a future medical solution. On the contrary, measurement and treatment devices were part of the situated practices through which the conditions emerged. Before I situate this approach within a turn towards practice that has recently taken place in the field of anthropology, I will elaborate on the problem of chronic health conditions as it is articulated in much health research and in light of the framework of the project in which I participated.

BARRIERS TO TREATMENT

Chronic health conditions are one of the most serious health problems in the Western world. Due to changes in demographics, life expectancy and life conditions, the pattern of diseases in the population of the western world has changed from acute and curable diseases to chronic conditions in need of ongoing care (Jørgensen 2005). An increase in methods for testing and screening combined with the emergence of epidemiological studies that allow researchers to calculate future risks associated with various kinds of behaviour, has made it possible for several chronic conditions to be diagnosed earlier or even prevented (Lupton 1995). The market for medical treatment is also rapidly developing and the possibilities for treating chronic conditions constantly increase. In a report on chronic health conditions, the Danish Health and Medicines Authority observes that despite an increase in the documented effect of treating chronic conditions along with evidence-based recommendations for optimum treatments, not all patients benefit from these recommendations (Jørgensen 2005:13). This is problematic for people who must live with what were otherwise avoidable health issues and for the society covering the costs of an unhealthier population (ibid.). The areas of diabetes and hearing loss are no exceptions to this development.

Type 2 diabetes is growing at a rate that has been termed epidemic. An estimated 382 million people worldwide have diabetes, while 592 million are predicted to have the disease in 2035 (International Diabetes Federation 2013). Type 2 is by far the most common type of diabetes, accounting for 90% of all diagnoses. The onset usually occurs after the age of 40 with an average debut of 60-65 years, but more recently it has been diagnosed in younger people. The reasons for developing type 2 diabetes are not known, but risk factors include obesity, physical inactivity, advancing age and family history of diabetes (International Diabetes Federation 2013). In type 2 diabetes, the body is either no longer able to produce sufficient amounts of insulin, or cannot respond to the insulin. The condition may cause only vague or no symptoms and can remain undetected for many years. However, it is a disease that can cause significant ill-health. A significant number of patients suffer from vision loss (7%) or blindness (1.5%), dialysis-dependent renal failure (4-8%) or neuropathy (25-40% after 10 years) that can ultimately lead to ulceration and amputations (Danish College of General Practitioners 2012). The most common cause of death amongst diabetes patients is cardiovascular disease, and in 2013 an estimated 5.1 million people died from the complications of diabetes (International Diabetes Federation 2013).

Hearing impairment is also a widespread condition affecting more than 34 million people worldwide, and is estimated to affect more than 50 million people in 2050 (Kockin 2007, 2009). Risk factors for acquired hearing loss include noise exposure, advancing age and family history of hearing loss (American Speech-Language-Hearing Association 2014). In acquired hearing loss the hair cells of the inner ear have often been damaged over time. The damage is most likely to affect the hair cells closest to where the sound enters the inner ear, and these hair cells are responsible for the higher frequencies important for understanding speech (Elberling & Worsoe 2006, Hougaard 2013). As a consequence sounds gradually become harder to distinguish, speech becomes indistinct, and conversations get difficult to follow (Elberling & Worsoe 2006). For these reasons it becomes more difficult to take part in everyday social life. Research has shown that hearing impairment may cause social isolation and low self-esteem (Christensen 2006). More recently, hearing impairment has been associated with the development of dementia (Lin et al. 2011).

These figures draw a clear picture across the two disease areas; the number of people who are affected is increasing and the consequences of not treating the conditions may be severe. Within the field of health behaviour, researchers seek to explain drivers of and barriers to changes of health behaviour. In the transtheoretical model of change, several models from psychotherapy are integrated to describe how changes in health behaviour take place. The model describes changes in health behaviour as a process with six identifiable stages where the patient's intention and confidence in his or her own abilities to undergo change gradually increases (Prochaska and Velicer 1997). There are other and more sociological approaches explaining how people handle health issues, including Profiles of Attitudes towards Healthcare (PATH), which consists of a typology of the U.S. adult population, describing nine different profiles of health behavior (Navarro 2008). Unlike the psychotherapeutic approach, the focus is on demographic, socioeconomic and personal differences as aspects of health behavior. In the areas of hearing loss and diabetes, expectations of the specific treatment devices are also often included in explaining the resistance to treatment. Studies have shown that wearing a hearing aid is associated with the stigma of old age and debility (Arnold and Mackenzie 1998). People who need hearing aids resist them in the belief that the aids are uncomfortable and will not restore hearing to normal (Hougaard and Ruf 2011). In the case of people with type 2 diabetes, the reluctance to start insulin is often explained by concerns about the routine and consequences of the treatment. A major concern is that the treatment may cause the content of glucose in the blood drop below normal levels, a condition known as hypoglycaemia. Since insulin injections mean that the patient needs to administer an injection, the fear of the needle is a well-known impediment to treatment. Research has also shown that some people fear the restrictions on their daily life that come with a daily routine of injecting. Finally, insulin is associated with weight gain, and since many people with diabetes are already overweight this side effect becomes a significant deterrent (Larkin et al. 2008).

While most of these studies point to subjective reasons for not following treatment recommendations and place responsibility for compliance on the individual, a recent turn in the field of public health research distributes the responsibility amongst numerous actors. The relation to the health care professional is ascribed great importance, and the concept of compliance is replaced with adherence, to underline the responsibility of the health care professional (Sabaté 2003). Even if this approach breaks with the focus on the individual, it still attends to ‘rational use’ of medicine and ‘barriers’ to obtaining this (Sabaté 2003:v).

A similarity between the approaches outlined above and the initial framing of my research project is the assumption that we need to understand what hinders people from doing what would be most rational in terms of treating diseases and taking care of their health. From this outset, whether or not a condition is treatable depends on its responsiveness to treatment and is a concern for biomedical research. The concern for social science becomes a matter of understanding what hinders people from adhering to treatments that the scientific evidence claims would be beneficial for them.

‘Illness and disease’ as a clinical tool

Medical anthropologists have often criticized biomedicine for its depiction of diseases as universal, neutral and objective biological or psycho-physiological abnormalities, in a way that does not reflect the social complexity and historical processes in which diseases are embedded (Mattingly 1998:276f, Hahn & Gaines 1985, Janzen 2002). An important anthropological contribution has thus been to situate medical practice in its cultural context (Kleinman 1980). Drawing on Eisenbergs’s distinction between disease and illness, Kleinman refined the division of pathology in two; the biomedical *disease* was contrasted with the patient’s experience and emotional response to his or her *illness* (1980:72f). Where *disease* refers to the biological malfunctioning and is related to the medical realm, *illness* includes personal and social responses to the malfunctioning and interpersonal interaction within the family and social network (Kleinman 1980:72). *Disease* affects the body and individual; *illness* may affect both the individual and the family. Kleinman stresses that illness and disease are not entities, but explanatory models anchored in different social arrangements. The dichotomy between these explanatory models was followed by a critique of modern western medicine for striving only to treat disease and not to cure illness (Good and Good 1981). One of the arguments put forward was that clinicians should take the patient’s experience and life world as the starting point for treatment. The distinction between illness and disease is considered useful way for clinicians to understand the patient’s subjective experience and perception (Janzen 2002).

This line of argumentation has since influenced the field of medical practice. General practitioners in Denmark are taught to see the patient holistically, not as a person with a specific disease (Hollnagel et al.1989[6]). The statement of aims for the education in family medicine stipulates that doctors, in negotiating treatment plans with their patients, ‘deal with health problems in their physical, psychological, social, cultural and existential dimensions’ (Danish College of General Practitioners 2007). Along the same lines, some researchers in the field of audiology argue that a paradigm shift is taking place from a focus on technological aspects of treatment towards person-centred care (Hickson 2012). Other researchers are more critical, and argue that in a field that focuses on scientific documentation and evidence in guidelines for treatment, few practitioners actually integrate the many aspects of health care issues, and as a consequence the humanistic understanding of health problems only superficially covers a

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[6] I came across this book as it was placed on the shelf in one of the clinics, where I did fieldwork. The book is part of the curriculum for general practitioners in Denmark.

hierarchy of knowledge where scientific facts are on the top (Martinsen in Plough Hansen 2004:96f).

My turn to the conditions as they emerge as locally produced phenomena may in this light be read as a critical relocating of the problem of chronic conditions from a realm of biomedical research and practice to the lifeworld of the people who suffer from them. My errand, however, is not to examine if doctors or researchers have failed to understand the complexity of patients' illness experiences, just as I am not interested in exploring how and why patients lack an understanding of the necessity of treatment. In contrast, I am interested in learning from doctors and patients; learning how they practically engage in knowing and handling their conditions. In making the matter of treatability an empirical question, I start with the practical processes in and through which participants build their understanding of the world by engaging in it. This involves another kind of relocation—from perspectives on the condition, to the practical production of them. It is a relocation that is critical of what we tend to take for granted, not critical of the medical practice.

ANALYTICAL TOOLS

The primacy of interaction

In the following, I will situate my analytical stance in the field of practice anthropology. More specifically, I argue for a primacy of interaction and see phenomena like subjects, objects and diseases as emerging in and through everyday practices. I draw on methodological approaches that emphasise practice, especially American pragmatism, praxiography and ethnomethodology, all of which I will discuss in more detail. Following a more general tendency in anthropology, my position is a turn towards practice. For a long time anthropology had been concerned with rituals, cosmologies and symbols – and their inherent logic. In the 1980s this focus was superseded by an interest in the problems of everyday life (Whyte 2004). Ortner argues that the practice theorists of the 1980s sought to understand how systems are produced and reproduced. They did not deny the determining effect of structure on human action, and the study of practice was not an alternative, but rather a necessary complement to the study of system and structures (Ortner 1984:146f). Attention has lately turned towards people's handling of the world in order to understand just that: the practical doing and being in the world. This turn is inspired by phenomenology and pragmatism (Hastrup 2005), and the starting point is no longer to bridge the gap between structure and actor, but a dismissal of any determining structure. In this spirit, Jackson instructs: 'do not look behind phenomena; they themselves are the truth' (Jackson 1996:11). There are no explanations to be sought beyond the emerging world.

This commitment to viewing the world as emerging from local practices differs from another dominant theoretical approach in medical anthropology inspired by the work of Michel Foucault. According to Foucault, the state and its political power play a central role in the analysis of health care. The modern period is marked by an era of 'biopower', a technology of power for 'achieving the subjugation of bodies and the control of populations' (Foucault 1990:140). This modern power over life is a technique working in two basic forms: by disciplining the individual body and by regulating the population. With biopower, enforcement by law is partly replaced with governance by norms (Kelly 2013:101f). Rather than separating the legal from the illegal, biopower works in a much more complex form by establishing 'various norms around which it can be decided what is normal and abnormal' (Kelly 2013:102). Petersen and Lupton argue that contemporary health interventions promote the body as a project to be worked on by the individual (1996). Due to the increased availability of data from population studies it is possible for epidemiologists to calculate the risk of particular behaviours (drinking, eating, exercising etc.) that are thus transformed to 'lifestyle' behaviours. As a result, individuals are ascribed great responsibility for their own health as their everyday behaviour is seen to impact the likelihood of falling ill or staying healthy (Petersen and Lupton 1997). Bodies are constructed through political powers, and the disorders of the late modern bodies are closely related to preventive efforts and self-care (see also Katz 2000).

Where the Foucauldian studies are concerned about the way in which norms and powerful representations of the world permeate our society, medical anthropology that emphasises practice is concerned with the way in which people in specific situations handle the discourse, how they use it or avoid using it in dealing with specific problems (Whyte 2004:49). What is at stake is not how subjects are regulated by norms, but how people handle specific problems and dilemmas and apply the norm as a resource in that regard.

Pragmatism

From perspectives to practices

As I started to work on my doctoral research, I was strongly influenced by American pragmatism, as it was formulated by the philosopher John Dewey (1925, 1929), and as it has been applied in anthropology (Whyte 1997, 1999, 2004, Hastrup 2005). A consequence of this point of departure is that conditions are not examined as bodily entities that may be understood differently from perspectives in and beyond the clinical encounter as suggested with the distinction between illness and disease. Instead, I see health conditions as emerging from practical engagements of knowing and dealing with problematic situations. Patients' and doctors' understandings of health issues are not separate views of the same object, but the result of situated and practical engagements:

> If we see that knowing is not the act of an outside spectator but of a participator inside the natural and social scene, then the true object of knowledge resides in the consequences of directed action. When we take this point of view [...] there will be as many kinds of known objects as there are kinds of effectively conducted operations of inquiry (Dewey 1929:157)

In this pragmatic understanding, we are not subjects gazing at the world, but inquirers learning about it by acting in it. Dewey's critique of the spectator theory is a critique of the philosophies that see our experience of the world in terms of vision, as if we only know some vague appearance of the world, which differs from the real world (1929:19ff). For him, the craft of knowing resembles more the qualities of the hand than of the eye, since we know the world by acting in it: 'it is not experience which is experienced but nature – stones, plants, animals, diseases, health, temperature, electricity, and so on. Things interacting in certain ways *are* experience' (1925:12)[7]. This reflects the philosophical position that nature and experience are not separate, but mutually emerging through practice. The methods we apply, as we find out about the world cannot be separated from the object of knowledge we produce. In other words, matters of ontology and epistemology cannot be separated, since knowing the world is an always embodied and concrete practice in the world (Dewey 1925, 1929). According to Dewey, we relate to the world in constant movement between acting, reflecting and being in the world (1925).

We may consider this theoretical standpoint to be quite pioneering since many recent contributions are concerned with knowing, and acting as necessarily embodied practices located in particular settings (Suchman 2000:312)[8]. In the field of medical practice, a recent contribution to this field is *The Body Multiple* by Mol. In this book, Mol undertakes what she terms an empirical philosophical study of the way medicine deals with the body and its diseases (2002: vii). The subtitle, *Ontology in Medical Practice*, indicates that Mol is not interested in medicine as an epistemological practice, but as a reality-building activity. Her point of departure is a movement away from subjective perspectives to a foregrounding of the practicalities in and through which diseases are produced:

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[7] The context in which Dewey's writing is situated is a debate in philosophy. He is arguing against the tendency to divide experience from nature, and epistemology from ontology. In particular, he is critical of Kant, who distinguishes between the world as it appears for *us* due to certain features of our cognitive abilities and the world in *itself* (Kant 1993). Dewey sees experience as situated in and emerging from our interactions with the world we live in, not conditioned by given abilities of our minds (1925).

[8] Suchman mentions symbolic interactionism, actor-network theory, cultural anthropology and ethnomethodology as examples of such intellectual traditions.

> If practices are fore grounded there is no longer a single passive object in the middle, waiting to be seen from the point of view of seemingly endless series of perspectives. Instead, objects come into being – and disappear – with the practices in which they are manipulated. And since the object of manipulation tends to differ from one practice to another, reality multiplies (2002:5)

From this starting point, she turns to an empirical or what she terms a 'praxiographic' study of atherosclerosis. The term ‘praxiography’ denotes her ethnographic strategy of foregrounding practicalities, and the ways in which diseases are *done*. It draws attention to ‘the techniques that make things visible, audible, tangible, knowable’ (2002:33). She conducted her research in several departments of a Dutch hospital, where atherosclerosis was treated in different ways. She shows how atherosclerosis was identified as a ‘thickening of the intima’ by use of a microscope (Mol 2002:30). In this description atherosclerosis was easily identified, since it was a visible and describable phenomenon. Mol immediately notices that this was but one of multiple enactments of the disease; an enactment involving not only the limb cut open, but also the microscope and the pathology resident. Other enactments of atherosclerosis took place in the outpatient clinic where doctors examined patients and interviewed them about their symptoms, pains and capacities to walk. The home was yet another site, where the arthrosclerosis came to be, as people engaged in practical matters of living with a leg that hurts (2002:15). She situates her analysis of these practices in opposition to the distinction between illness and disease. She refrains from the position that she terms ‘perspectivalism’ according to which arthrosclerosis in the hospital and homes are seen from diverging perspectives of doctors, nurses, technicians and patients. Her critique of this position is somewhat similar to Dewey’s critique of the spectator, who passively gazes at the world, and she argues that we cannot divide the body and its ailments from the tools and methods we use to inquire about it and what we consequentially come to know about it. Her argument resembles an empirical translation of some of Dewey’s theoretical thoughts[9]. Where he critiques modern philosophy for dividing our experience from nature, she critiques ethnographic studies of western modern medicine for dividing peoples’ perspectives from the ‘disease itself’ (2002:12). With the term ‘enactment’, Mol suggests that we interrogate diseases as they are done. In contrast to ‘performance’, 'enactment' bears no connotations of a front stage where actors engage with each other and a backstage where hidden perceptions are formulated. There is nothing behind the enacted world; it *is* reality.

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[9] It should be mentioned, that Mol critiques pragmatism as formulated in the work of Engelhardt for not analyzing the relations between various medical practices and theories, and thereby merely describing the diversities, while ignoring the achievement of making the world hang together, so it does not fall into fragments (2002:111, 6). A more important difference for my work, however, lies in the primacy Dewey ascribes to experience for our relation to the world, whereas Mol ascribes primacy to practice and leaves ‘the actors vague’ (2002:33). I will discuss the implications of this discrepancy at the end of the chapter.

A consequence of this approach is that it creates symmetry across different sites in the hospital as well as outside it, since in each site, the disease is 'being done' (2002:32). This symmetry is not based on a moral concern for the patient's perspective, but an ontological symmetry that situates disease as part of practice, not preceding it. While each enactment brings about a distinct version of the disease, each enactment is equally real, but the result of different manipulations[10]. This approach allows me to analyse the health conditions as they are done across the clinical setting and the home as ontologically equal, since both are the results of practical engagements.

Data are 'taken', not 'given'

As I noted earlier, a central tenet of pragmatism is that we know the world by engaging in it, not from gazing at it or reflecting upon it, but by actively solving problems as they arise. Along these lines, Dewey rethinks the notion of 'data'. The word originates from the Latin 'datum' and literally translates to that which is 'given' (Oxford English Dictionary 2014). Rather than viewing data as 'given' before our eyes, he suggests that we denote data as what is 'taken'. What we know about the world does not emerge from separate entities available to our sensory experience; data are selected with the purpose of locating and solving problems (Dewey 1929:142-3). When a patient presents a problem for his physician, Dewey writes, the problem presentation does not make up an object of knowledge, but 'something *to be* known' (1929:143). The patient's problem sets a problem for inquiry, and in light of this, the doctor performs certain clinical operations that supply the evidence to be interpreted. Not all sense data are included: 'in no case are the data the whole of the original object; they are material selected for the purpose of serving as evidence and signs' (1929:140). The data are thus the result of directed inquiry, guided by an aim of knowing what is needed to relate the evidence to a medical intervention. The observations do not mean something in and of themselves, but only as the physician interprets them and relates them to a store of knowledge. Through this skilled work, the physician produces data about the disease: 'as they are deliberately selected, being discriminated by special technical operations, they become data' (1929:143).

The spectator mistakes the data thus produced for 'givens', while they are emerging as the physician inquires about the problem his patient presents. Data are refined products of thinking and emerging from practical engagement. We do, however, talk about the body and the ailment as isolated entities, but this is an analytical device to talk about things as if they were separated,

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[10] We might be inclined to think that the result of this observation is that the world fragments into an infinite amount of objects. Part of Mol's project however is to demonstrate that the body is not one, nor many, but multiple. What make it diverse are the ever changing practical enactments, but at the same time they are kept together by coordinating practices (2002).

when they are entangled. We are only mistaken, if we take the products of our analysis to have ontological priority (Boisvert 1997:20). Dewey therefore cautions us to start with things in their complex entanglements, as they emerge before they are transformed into data and objects of knowledge:

> It [the pragmatic empirical approach] warns us that all intellectual terms are the products of discrimination and classification, and that we must, as philosophers, go back to the primitive situations of life that antecede and generate these reflective interpretations, so that we re-live former processes of interpretation in a wary manner, with eyes constantly upon the things to which they refer. Thus empiricism is a truly critical method; it puts us knowingly and cautiously through steps which were first taken uncritically, and exposed to all kinds of adventitious influence [...] the notion cautions us that we must begin with things in their complex entanglements rather than with simplifications made for the purpose of effective judgment and action (Dewey 1925:387)

The consequences of this approach for an ethnographic study is to draw attention to the processes in and through which people 'take' certain features of the world, interpret them in light of the purpose of their inquiry and insert them into a context of directed action. Isolated entities as the body and its ailment are constructions, products of selective emphasis (Boisvert 1997:22), and Dewey has an abiding concern for interactional processes. Leaving behind the commonly accepted distinctions between the body and the mind, the pathological and the normal, the object and the subject we may instead turn to the practices in and through which these concepts emerge. The world is thus a matter in the making, emerging and changing as we interact with it, not something given that may be gazed upon from seemingly different perspectives. To understand how a disease thus emerges and is known to be in need of treatment, we must empirically scrutinize the situated practices of dealing with it.

Directed action

The position I have argued for shares many similarities with the field of science technology studies (STS). In this varied field, the concerns for how facts are fabricated in the laboratory and medical diseases are constructed in clinical practice are central issues (e.g. Latour and Woolgar 1986, Berg 1992). The work of Mol is usually situated within this field. Much like the position I argue, the field of STS reframes what we usually take as natural phenomena as emergent through sociomaterial interactions. There is, though, a fundamental difference in the figuring of human beings and their capacity to act between Mol and Dewey. I agree with Dewey when he describes human beings as inquirers who solve problems, and therefore he sees human action as a directed activity guided by an objective. In *The Body Multiple*[11], Mol suggests that we see people primarily as actors, and leave concerns for their intentions behind. Doctors, patients and nurses take part in enactments of the disease, but only as they engage in movements, conversations and manipulations of tools. The world thus emerges, but also ceases to exist with the practices (2002:5). This pictures a flat ontological landscape where there is nothing behind or above, no structures that determine actions and no intentions that direct human action. As we will see in chapter four, this is problematic because people do not only act in the world, but also 'take' certain events to be of importance at the expense of others. They assemble and interpret the meaning of their health conditions, not only by acting, but also in composing meaningful accounts about their present and future, and from these understandings seeking to deal with problematic situations.

Mol and Dewey agree that we should leave behind our commonly accepted understandings of the experiencing *subject* and an *object* being known, and attend to the practices with which the world we inhabit emerges. But at that point their paths diverge. In Mol's terminology we thereby leave behind the objectified body-we-have and the subjectified body-we-are in favor of an examination of the body-we-do. This movement locates diseases in the practices with which they emerge and disappear. Dewey in contrast replaces the subject-object dichotomy with a trinity of the *inquirer*, a *subject matter* and an *objective* (Boisvert 1997:36). In this framework, people are active and embodied inquirers engaged in examining a particular subject matter with the objective of knowing and resolving what they find problematic. Mol characterizes her study as a movement away from epistemology, focusing on the multiple enactments of the world and how these are practically coordinated. Dewey, on the other hand, argues that nature and experience cannot be set apart and takes the inclusive integrity of experience as his starting point; including both *what* men strive for and endure, but also *how* they act and are acted upon (1925:18). Life is a comprehensive activity, Dewey writes, and 'only upon reflective analysis does it break up into external conditions – air breathed, food taken, ground walked upon – and internal structures – lungs respiring, stomach digesting, legs walking' (1925:19). We analyze the world in order to be able to act in it, and our agency and subjectivity are emergent from our analytical emphasis and interpretation of the world. The importance of interaction cannot be overemphasized; the world is made up by things interacting, not by isolated entities, and our capacity to act in the world emerges from our interactions with it. In contrast to Mol, who sets *meaning* and *doing* apart, I want attain to practices as meaningful productions of reality.

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[11] I refer to this work, since other works like *The Logic of Care* seem to be infused with another understanding of medical practice. In that work, her main concern is not about emerging ontologies, but about the importance of skilled care in medical practice. For simplicity of my argument I use *The Body Multiple* as an example of a STS study in medical practice.

Ethnomethodology

Like pragmatism, ethnomethodology is an empirical approach that sets interaction first. It has been suggested that ethnomethodology may be considered a development of some of pragmatism's fundamental ideas into the empirical sciences (Emirbayer and Maynard 2010). In contrast to Dewey's philosophical project, the field of ethnomethodology is rich in detailed empirical studies of reality-constructing practices, and my work draws on several concepts developed in this field (Suchman 2007, Gubrium and Holstein 1997, Goodwin 1994, Heath 2006). Before I elaborate on the key analytical concepts I use, I will introduce the methodological stance[12].

Matters in the making

Ethnomethodology is an alternate sociology developed by Garfinkel in the 1960s. It differs from other sociological traditions, most importantly the Parsonian tradition that seeks to explain behaviour in terms of societal norms and structures. Ethnomethodology is concerned with how members of society *do* order, rather than how they are animated by it (Garfinkel 1967). Practices are orderly in their own right and are not to be explained with the rules that they make observable. In other words, ethnomethodology is an investigation of the rational properties of practical actions as 'contigent ongoing accomplishments of organized artful practices of everyday life' (Garfinkel 1967:11). The emphasis is on how people produce what is commonly taken for real, or in the words of Garfinkel, how it is 'procedurally enacted' (1996:20). *Procedural* does not refer to process, but to labour (1996:6), and the *work* inherent in accomplishing the world as real is often emphasised. As Pollner articulates it: 'The phenomenon *par excellence* is not the world *per se* but worlding, the work whereby a world *per se* and the attendant concerns which derive from a world per se – truth and error, to mention two – are constructed and sustained' (in Gubrium and Holstein 1997:39). The existence and maintenance of the world we take for granted is the result of laborious interactions and interpretive work; it is a matter in the making. In that regard, ethnomethodology shares the radical empirical approach with pragmatism. It suspends everyday assumptions in order to examine the way in which 'the apparent concreteness of lived experience is assembled' (Gubrium and Holstein 1997:41). The starting point is social interactions, which are seen as reality-constructing practices.

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[12] There are important methodological differences between ethnomethodology and ethnography (Pollner and Emerson 2001). In chapter two, I will describe how the discrepancies emerged as problematic during my fieldwork and were transformed into a methodological sensitivity.

Treatability

Ethnomethodology locates the achievement of the social world in everyday situated practices. It is concerned with the methods for producing shared understandings that we take for granted, and views such understandings not as preconditions for interactions, but emerging from them. A methodological procedure in the field is to *respecify* what is commonly taken for granted and used as a *resource* for explaining an empirical phenomenon and turn it into the *topic* for research. In the approach I have called 'barriers to treatment', it is a premise that diabetes and hearing loss are treatable; it is a *resource* for explaining human behaviour. In this thesis, I want to explore treatable conditions as locally produced and interactive phenomena; I make it the *topic* of my research. Rather than assuming that a condition is treatable and then explain why evidence-based recommendations are or are not always followed, I take treatable health conditions to be a local accomplishment of practical interactions.

In a study of doctor-patient-interactions, Stivers develops an ethnomethodological understanding of *treatability* as an activity by which patients establish that treatment is directly relevant (Stivers 2002)[13]. In her study of pediatric encounters, Stivers observes that some parents, in presenting their problem to the doctor, describe only their child's symptoms, while others suggest a diagnosis. In the latter case, the presentation anticipates the doctor's judgment and makes treatment directly relevant. She goes on to show that doctors respond differently to the different formats of problem presentations, and that the candidate diagnosis is treated as having adopted a stance that they are seeking treatment.

Stivers' notion of treatability is concerned with a specific activity found in clinical encounters between doctors and patients: that of patient's problem presentation. In my work, I want to move beyond this narrow focus and investigate other activities in which the need for treatment is produced. What I do take with me from Stivers' approach is the focus on interactional work of aligning – or mis-aligning – of the problem of a condition to the anticipated treatment. However, my approach adds a lot more to treatability: it is more than a practice by which patients seek treatment. I want to explore how the need for treatment emerges across practices of measuring, assessing and negotiating – in making sense of and finding out what to do about a condition. With this understanding of treatability, the concept is broadened from a linguistic practice in the clinic to multiply distributed sociomaterial practices constructing a disease as in need of treatment.

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[13] In the studies of doctor-patient-interactions, researchers have shown that patients make an effort to show that their visit is a legitimate subject of doctor interest or intervention, and that their problem is worthy of medical attention (Heritage and Robinson 2006:58). Establishing that a problem is *doctorable* is hence a fundamental aspect of the justification of visiting the doctor (Heritage 2009). This practice conveys a stance towards the problem in terms of its *doctorability*. Stivers' concept of treatability is a development of doctorability to denote practices that do not only include problem presentation, but also point to the relevance of treatment.

I respecify treatable from a given relation between a disease and a particular treatment to an 'effect of practices that are multiply distributed and contingently enacted' (Suchman 2007:267). In other terms, my thesis is a retelling that articulates the practices of achieving conditions as treatable.

Configurations

A central contribution in the borderlands between anthropology and ethnomethodology is Suchman's work on human-machine interactions (2007). With the concept of 'configuration', Suchman suggests that we think of technology as *materialized figuration* or an arrangement that affects particular meaningful associations of persons and objects (2007:227). The concept is inspired by Donna Haraway, who argues that all language, including technological language, is figural and that we think of technology as figural assemblages embodying shared meaning (Haraway 1997:23). The prefix *con-* indicates that the technology is figured *with*, or in relations between humans and things. The concept is interesting in relation to treatment technologies in diabetes and hearing care, because it stresses the way in which technologies figure a disease *with* a treatment.

In both Haraway's and Suchman's work, 'configuration' is used as an analytical strategy of drawing attention to the emergence and contingency of situated practices. Haraway uses the concept in a critical historical analysis of the rise of modern science. The central figure is the 'modest witness', a self-invisible scientist whose subjectivity is objectivity (1997:24). The scientist is a figure that merely witnesses the world as it unfolds and whose narrative about the world defines the facts. In relation to this figure, science is articulated with an apparent transparency and non-appearing of the particular circumstances in which it is produced. Haraway argues that all knowledge is situated and embodied, it is not seen from above but always from somewhere in particular (1997:33, 1988:583f).

Suchman uses configuration to explore the relation between humans and interactive artefacts. Where Haraway makes a historical analysis of modern science, Suchman takes the concept into a moment-to-moment analysis of sequential interactions between humans and machines. She is concerned with the way in which machines figure human action, and examines, amongst other things, how people in a research centre interact with a photocopier. She observes that intelligent machines are designed based on the understanding of human behaviour as a planned and purposeful activity, while her studies show that human action is situated in particular circumstances and characterized by improvisation. Her detailed analysis of humans and machines in interaction shows that action is concrete and embodied practice conducted with artful adjusting to its circumstances. In both analyses there is a critique of a pure form in favour of a situated accomplishment—a move from objective to situated knowledge, and from planned to situated action.

There is a similar movement in my analysis, as I set out to locate the practices of treatability. I am critical of treatable diseases as a detached truth that can be described from a point of no-where. I argue instead that treatability is a situated practice in and through which diseases are enacted and made relevant to treatment. The concept of configuration points to the relation between the disease and its treatment. The material figuration that interests me is the treatment device. Every artefact designed to solve a particular problem relies on and materializes an understanding of that problem (Suchman 2007). The hearing aid and insulin pen are not exceptions. When a patient faces the prospect of becoming a user of the treatment device, the disease is related to in a certain way. When hearing loss is figured in relation to a hearing aid, it is configured as a problem that is solvable by amplification into the impaired ear. The treatment technology does not only solve the problem of the disease, it also shapes the representation of disease problems (Keller 1992). I am shifting from a question about choice and barriers, to a matter of configurations between humans and things. From this point of departure, human action is not a matter of adherence or lack thereof to a given rational course of action, but embodied, situated practice.

As an analytical strategy, the focus on figuration has another important consequence for my work. Since I contend that diseases emerge through interactions, the configuration of treatable conditions is a complex matter of relations. In Suchman's analysis a user interacts with a photocopier, and the figuring of human action by the machine is challenged by the situated actions of its user in moment-to-moment interactions. I am studying pre-users, people who do not have a device in their hands. They relate to the prospect of becoming users as they interact with their doctors, measuring devices, sounds, spaces, food items, medical evidence, family members, and others. It is through these numerous relations that hearing loss and diabetes are configured as treatable conditions. My empirical focus is not on moment-to-moment interactions with a present technology, but on all kinds of relations between the treatment device and the pre-user. As we will see in chapter six, a consequence of this analytical strategy is that the potential for intervening is not so much about providing people more information about the treatment or convincing them that it will be good for them, but about intervening in the relations in and through which the diseases are configured.

OUTLINE OF THE THESIS

This thesis examines how two health conditions – diabetes and hearing loss – are handled in concrete and embodied situated practices. From the understanding that knowing and intervening are inseparable activities, it explores how problems of each health condition emerge and are handled in everyday practice.

In structuring my material it was a constant challenge to divide elements that gained meaning through their relations to each other; the medical condition in relation to its treatment and the clinical practice in relation to the everyday life with the conditions to mention a few. In writing up my findings, I have divided the enactments of the conditions from the treatment technologies. In chapters three and four, I examine how the conditions emerge as problematic and are dealt with, first in the clinic then in the home. These chapters serve as an unfolding of the multiply distributed practices in which the two conditions are enacted. In the following chapter five, I then turn to the treatment devices and discuss what happens as hearing aids and insulin are presented as possible solutions to hearing loss and diabetes.

Part of the project was also to integrate opposites that did not appear to have an immediate relation; the diabetes compared to hearing loss, and the situation in Denmark in relation to the situation in the USA. I have decided to structure my thesis as an ongoing comparison and contrasting of the two health conditions, to articulate difference between them and gain a richer understanding of both. As for the two countries, the comparison is more subtle, as I have decided to structure the thesis around the similarities rather than the differences. I argue, that in spite of the apparent differences between the US and Danish health care systems, there is a great deal of resemblance between the practices of treatability in the two countries.

Chapter two, 'Field work', describes my own knowledge-producing practices and introduces the setting for my study. My doctoral research was part of a larger project, and certain topics were therefore given to me as premises for the research. I point to three important relations within which my work has been situated; the industrial relation within which I was working; the collaborative relation with design; and finally the relation to SPIRE and the perspective of ethnomethodology. Through the interaction with stakeholders and colleagues my object of study has been shaped and re-shaped, and an aim of the chapter is to make glimpses of the process visible. The setting for my study is described in terms of a treatment landscape within which doctors and patients are situated, and I account for the methods I have used to explore their everyday practices of handling the two medical conditions. Most importantly my methods include observations and video recordings in medical clinics and interviews in private homes, and I discuss the different ways in which they allow me to study everyday practices. The writing up was steered by an ethnographic curiosity, that was not mine alone, but emerged from conversations with others involved in the project, and developed from my tinkering with different analytical grips.

In chapter three, ‘Measurements’, I start unfolding the empirical question – how conditions emerge as locally situated phenomena – by exploring doctor-patient interactions. As the title suggests, the focus of the chapter is the embodied practices of measuring and producing the body as an object for medicine. I examine how medical evidence is produced in interactions, and how doctors and patients orient to the evidence as a truth about the body, but also read it in relation to the experiences of everyday life to render it meaningful. I draw on Goodwin’s ethnomethodological work on ‘professional vision’, as a situated and embodied practice, to understand the selective knowledge producing practice of foregrounding certain features of reality and coding them in a professional discourse to make a meaningful object of knowledge (1994). I argue that the body as an object and the patient as an acting subject are interactional achievements. By juxtaposing the two disease areas, I discuss the differences in capacity to know and take action ascribed to the patient.

In chapter four, ‘Situated Concerns’, I move beyond the clinic to explore how the two chronic health conditions are dealt with in everyday lives in the homes. As I made this displacement, I was no longer able to observe the moment-to-moment practices of dealing with the conditions. The subtle character of the conditions meant that they often did not appear problematic during most of the time I spent with my informants. People with a mild or moderate hearing loss mainly have difficulties when there is noise or many people talking at once, but conversing with me in a quiet room was not problematic, just like people with diabetes often were well regulated and did not sense any symptoms. I therefore took on the approach of seeing people as ethnographers in their own life. In line with the praxiographic approach that Mol advocates, I asked them to observe and describe problematic events (2002). From this position I explore what happens in situations where the conditions emerge as problematic and are dealt with. As I went on with this methodological approach, I soon realized that it ignored another important practice – that of knowing which events to include in the account. In the clinic, I argued that only certain features of the body and patient experience are foregrounded and assembled to the object of knowledge. In the home, people do something similar, as they take certain events to relate to their conditions, while others are left out. I propose that this skilled practice of knowing is crucial for understanding how conditions are constructed, and argue that we cannot think of people as mere actors and their actions as enactments without meanings. I argue that people act on the basis of situated concerns, because they care about something in particular, and they do not merely live through events of their life.

Chapter five, 'Configurations of treatability' examines how the problems of diabetes and hearing loss are transformed in the anticipation of treatment with insulin and hearing aids. While the two previous chapters have unfolded the diversity of the conditions, I show that the prospect of treatment entails a degree of regularity as only certain features of the diseases are foregrounded in relation to the treatment device, while others fade in the background. I use the concept of configuration to argue that the treatment devices are materialized figurations of the conditions. Particular aspects of the conditions are figured *with* the insulin and the hearing aid. The chapter draws on material from clinical encounters in what I term 'moments of treatment', where the treatment technology is discussed as a possible solution. I discuss such moments as particular occasions on which a medical condition is related to a technological device with transformative consequences. It is a matter of inquiring the problem and aligning it with the solution that does not follow a determinate sequence of events. In the 'medical model', a disease *first* produces symptoms, *then* the doctor investigates their cause and *finally* a diagnosis is set and rational treatment commences (Good 1994:8). A reversed model has been suggested, in which medicine is a 'driving force' as it targets a specific disease, with symptoms that are subsequently described for doctors and patients, who then recognize these and seek to treat them (Ecks 2013:8f). I argue that treatability follows neither of these temporal sequences of events; diseases do not exist independent from treatments as the medical model represents it, nor are disease categories determined by medicines. Treatable conditions emerge from situated, embodied practices in which technologies mediates diseases without determining them.

In chapter six, 'Situated reframings', I shift from the study of doctors and patients interacting to my own interactions with the companies involved in the project. The empirical focal point is an exhibition we designed and presented as the research project was coming to an end. The opening poster asked employees of the two companies 'Do we create problems or solutions?' to stimulate discussions about the role of treatment devices in configurations of diabetes and hearing loss. The exhibition was designed in an open-ended format and consisted of ethnographic material composed of stills and extracts of conversations recorded during fieldwork and critical design concepts. The ethnographic material was presented together with analytical questions, and the design concepts suggest different material figurations of the conditions in the attempt to provoke the audience to consider and discuss the assumptions on which their products are designed. The exhibition was set up in both companies, and we arranged guided tours during which our audience commented and discussed the ethnography and design. Based on an analysis of these conversations and written comments our visitors left, I argue that the exhibition opened up the problem-solution framework behind hearing aids and insulin pens. In these conversations, assumptions and understandings of the medical conditions, the treatment devices and their potential users were articulated and reframed.

In chapter seven, the conclusion, I look back at what I learned about how persons, medical conditions are related on particular occasions. I consider the consequences of my analytical strategy and suggest some implications of moving beyond the stance, I have termed ‘barriers to treatment’.

CHAPTER TWO

FIELD *WORK*

In the past chapter, I argued that the world we live in emerges with our practices of inquiry, not prior to them. My own field of study is no exception in that regard, and my methods for knowing share a great deal with the practices I study. My ethnography is an assemblage of field material, 'taken' for the purpose of solving a particular problem (Dewey 1929:142f). Like all knowledge, it is selective, partial and incomplete (Schmidt 2001:17f). The validity of an ethnography therefore does not only rely on its empirical foundation, but also on the visibility of the 'ethnographer's path' through the field research (Sanjek 1990:398f). The aim of this chapter is to account for the path I have followed, the choices I made on the way and the premises I worked within, to render the partiality of my ethnography visible.

Though my ethnographic material is 'taken', the frame that I worked within was to some extent 'given' with the contract I signed and the shared project I engaged in. Prior to my entry on the project, the two companies and SPIRE had formulated a research plan. My task was to understand why 'pre-users' delay the onset of treatment beyond the point where they can medically benefit from it and then to map out the 'barriers to treatment'. In other words, I was to study why people faced with a particular problem do not use an available solution. I soon learned from my fieldwork that people handled their hearing loss and diabetes in a number of ways and did not always see the treatment devices as future solutions. In many cases, they did not strive to become users, but aimed at postponing or avoiding this. As I posited that the insulin pen and hearing aid simply figured as future solutions to medical problems, it aroused my curiosity, not only about how the problems of hearing impairment and diabetes emerged and were handled but also how these practices related to the treatment devices. My search for an answer to these questions continued far into the work of writing up the thesis. As Sjørslev observes, it is not until the completion of giving form to the analysis that it becomes clear which events were important for the work and what thus make up the 'data' of one's study (1995). So the 'given' question and point of departure were transformed as I produced my own knowledge.

This chapter is an account of the premises I worked within, the setting in which my research took place and the methods I used. The field of my research emerged over the course of the project; it consists of the multiple sites where my research took place, and is formed by my interactions with my colleagues as well as the people I met in the field. Three relations are especially importance in the formation of the project: the industrial relation, the relation to design, and the relation to ethnomethodology. For each relation, I point to ways in which it shaped the fieldwork and analysis. After situating my own work, I describe the setting of patients and doctors who are dealing with hearing loss or diabetes in terms of the treatment landscape within which they are moving. I then discuss the methods I used for studying their practices of dealing with hearing loss and diabetes. Most importantly I discuss my observations in the clinics and the interviews in the homes. I end the chapter by contending that my empirical material and analytical strategy can be understood only as generated through the relations I engaged in throughout the research project.

THE FIELD

Fieldwork is the crux of anthropological methodology. The word originally emerged in anthropology to indicate that ethnographic *work* took place in the real world, in the *field* (Hastrup 2003a:13f). The classic image of the 'field' as the exotic and bounded site for months of focused observations and participation has been challenged and reworked within the discipline of ethnography. One approach that challenges the single-sited tradition is the multi-sited ethnographic practice emerging within the sphere of interdisciplinary research in the 1990s (Marcus 1996). According to this new mode of research, the ethnographer no longer studies culture as bounded to a single location, but moves out to 'examine the circulation of cultural meanings, objects and identities in diffuse time-space' (Marcus 1996:96). The object of study thus consists of cultural productions that are multiply situated. As a consequence of this approach, the work of the ethnographer is not confined to data collecting, but also involves locating cultural productions by making translations and connections between distributed sites (Marcus 1996). With the term 'location work' Gupta and Ferguson stress the importance of this process, not simply as a matter of shifting locations for the sake of shifting locations, but also as a matter of connecting to the logic of one's larger project and practice (1997:37). Locating is hence an ongoing project that is strategically worked on and which depends on relations to other people involved in the research, to the place where research takes place and the premises of the social life there. With this movement from *bounded fields* to *shifting locations,* ethnographic knowledge becomes a matter of situated intervention pursuing a specific aim (Gupta and Ferguson 1997:38).

This project was originally planned as a multi-sited ethnography that would take place in a number of clinical sites in two countries where barriers to treatment with hearing aids and insulin were assumed to surface. My location work, however unfolded with the project. I shifted from searching for situations where barriers emerged, to locating particular occasions on which the relations between diseases and treatments were enacted. In other words, I wanted to leave the 'barriers to treatment' approach, and turn to the practices through which members construct the world as real, and diseases as treatable. I have titled this chapter 'Field Work' to denote not only my ethnographic work, but also the work of constructing the field as a site for investigation. In relation to the people I study, I have observed that the world we live in results from the active *work* of reality construction (Gubrium and Holstein 2003). In the same manner, what makes up the field of my study is the result of ongoing 'field work'. This 'field work' stretches out and overflows the time of ethnographic research; it started with the framework I was given as I entered the project and runs far into the writing up of my thesis. My field is therefore the totality, not only of the multiple sites where I met doctors and patients, but also the companies where I spent time, the work with my supervisor group where we made decisions about the research and the ongoing conversations with my design colleague.

The industrial relations

My 'field work' is profoundly shaped by the interdisciplinary and industrially embedded research project 'Innovating with pre-users of medical devices' of which I was a part. The project aim was to create an understanding of the barriers inherent in the transition from 'pre-user' to user, and to develop methods that involved pre-users in innovation processes in order to uncover business opportunities for the companies. With my background in anthropology, my task was to study the barriers that inhibit pre-users from becoming users of medical treatment devices. My colleague on the project Janet Kelly, with her background in design, would then adapt user-driven innovation methods and identify the business opportunities that had been created from the ethnographic understanding, and examine the use of design methods in corporate innovation processes (see Kelly 2014).

Novo Nordisk

Novo Nordisk is a global healthcare company, and a world leader in diabetes care. The company holds a global value market share of more than 25% in diabetes care, and almost 50% of the insulin market. The company also has leading positions within haemophilia care, growth hormone therapy and hormone replacement therapy.

Novo Nordisk was founded in Denmark in 1923, and the head quarter is still located here. The company employs 14,800 in Denmark and approximately 38,400 employees worldwide in 75 countries with production in 7 countries. In 2012 Novo Nordisk had a total sale of diabetes care products of 65.5 billion DKK of which 49% is from sales of insulin. Its largest market, North America, accounted for 44% of the total sales.

The 'Innovating with pre-users of medical devices' project was established in collaboration with the department 'Innovation and Concept Facilitation' located in the Device Research and Development site in Hillerød, North of Copenhagen. The site is developing pens with which insulin is administered. The innovation facilitation is an internal consultancy unit, and employs approximately 10 people from engineering, design and ethnography. The unit works with user understandings for projects conducted within device research and development.

Oticon A/S

Oticon A/S is amongst the world's leading hearing aid manufactures. Oticon A/S was founded in 1904 by Hans Demant, whose son William Demant gave name to the Holding Company of which Oticon A/S forms part. The total revenue for 2013 was 9.2 billion DKK with hearing devices accounting for 87%. Oticon's largest markets are Europe and North America both contributing with 39% of the total revenue. Oticon and Oticon Medical together employ more than 3000 people worldwide, with 615 employees at the headquarters near Copenhagen.

The project 'Innovating with pre-users of medical devices' was first located in 'Centre for Design Thinking', an internal unit to promote user understanding and the ambition of a more user-driven, rather than technology-driven product development within the company. Six months into the project, the department was closed down, and the project became affiliated with the Eriksholm Research Centre, where a multi-disciplinary team of around 25 researchers work to identify new opportunities within audiology to lay the foundation for development of new concepts in Oticon

We started working on the project in August 2009, and we were both curious about commencing the work, since we were new both to the companies and university involved, and to each other. As industrial PhD students, we were employees in the companies. However, sharing our time between fieldwork and academic engagements meant that we were also 'visitors'. We were not counted in the workforce when tasks were distributed, but allowed to work as we wished on our own project. In both departments we each had a desk and were warmly welcomed. We participated in meetings, attended presentations and in both companies we were taught about the disease areas in which the companies were working.

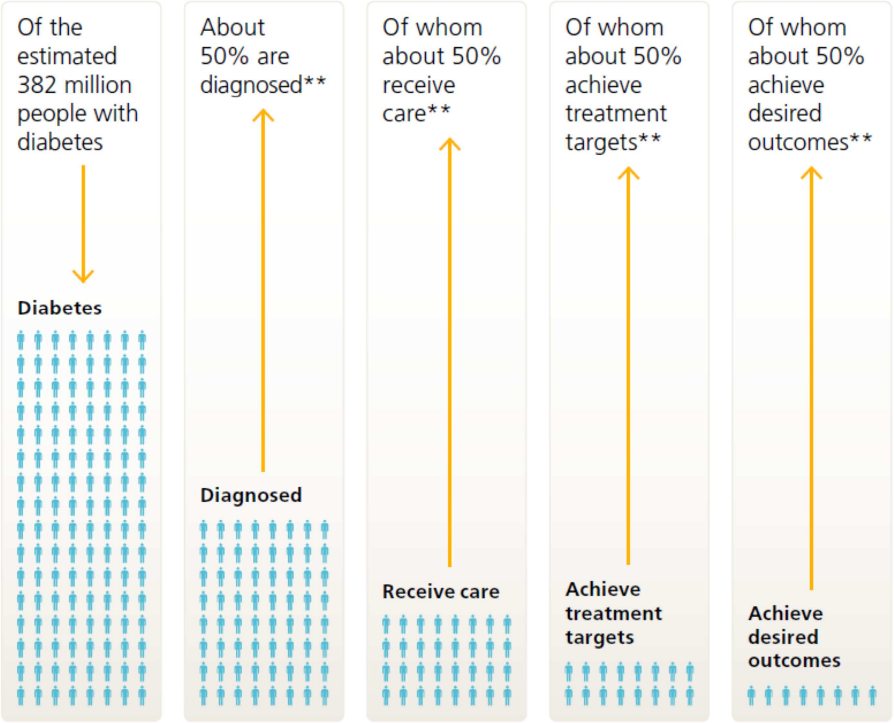
I was soon overwhelmed by the amount of knowledge the departments possessed about their users and slightly intimidated by the task of unearthing new insights. I was introduced to the Centre for Design Thinking in Oticon, where I was met with foam boards with user typologies, models of the user's social relations and photos from fieldwork in homes, on shopping trips and in clinics, all from studies conducted by ethnographic researchers. In Innovation and Concept Facilitation in Novo Nordisk, I saw boards that documented how users handle the insulin pen in moment-to-moment administration, and learned about the personas of diabetes patients. In addition, I was introduced to a vast amount of research on users and barriers to insulin initiation. In these first months, I did not think of these activities as part of my fieldwork, but as I am now writing up, I see them as an important beginning of my 'field work'. My entry into the companies was an inquiry into their understandings of potential users and their behaviour.

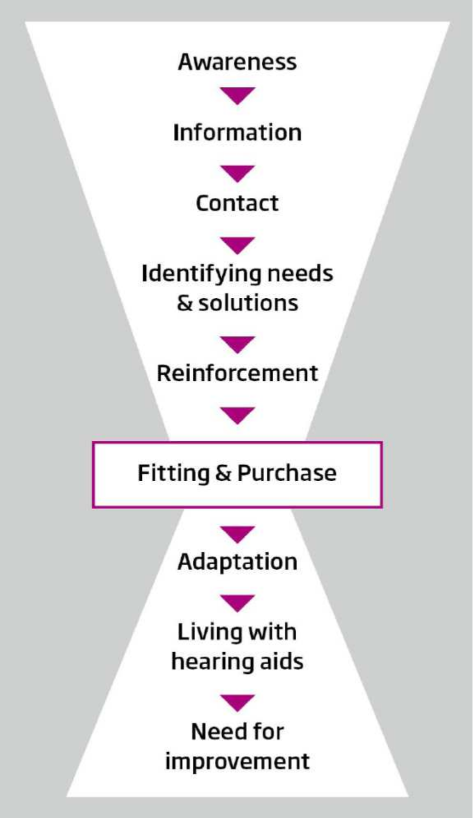
The pre-users of medical devices

In both cases, 'pre-users' were a large potential market for the companies. In Novo Nordisk, this was often talked about as 'the rule of halves' according to which only 50% of the people suffering from diabetes, are diagnosed, 50% of whom receive care, of which 50% achieve their treatment target and only 50% of these, or less than 10% of diabetics, reach the desired treatment outcome (see page 32). Drawing on the 'rule of halves' some people worked to find out what kept patients from achieving their treatment goals. Scientific studies were conducted in collaboration with academic institutions to understand 'barriers to improved diabetes management' (Peyrot et al. 2005a), and the 'resistance to insulin therapy among patients and providers' (Peyrot et al. 2005b). During my time in the company, the moment of initiation, where a patient starts the treatment with insulin injection was granted a great deal of attention. In 'Concept and Innovation Facilitation', where our project was based, a group of employees was studying the barriers that kept both doctors and patients from progressing to insulin treatment. As part of this process, the group summed up the key barriers to insulin initiation from previous qualitative studies. Among these barriers were patient-expressed concerns about insulin treatment. Key factors were negative

THE 'RULE OF HALVES'

'According to the Rule of Halves, only around 6% of people with diabetes live a life free from diabetes-related complications' (Novo Nordisk 2014a).





THE 'END-USER-JOURNEY'

'The end-user journey consists of nine stages that the clients experience on their way to better hearing. The journey begins when they first become aware of a potential hearing loss and concludes when they have become experienced users' (Oticon 2014).

The first two stages involve recognizing the hearing loss and seeking information about treatment. From the first contact follow interactions that lead to the purchase and transition to use.

expectations about the treatment regimen, including inconvenience and the pain involved in daily injections at home. It was noted that people feared a permanent transition to a more serious disease and associated the initiation with failure, shame and guilt. The identified barriers also comprised some concerns expressed by health care professionals. Amongst these was the health care professionals' reluctance to initiate insulin because they lacked experience in teaching their patients to use the device. Another insight from the previous studies was that some professionals thought their patients might be frightened by insulin and consequently stop coming in for review visits. Finally the risk of hypoglycaemia, in which the level of glucose in the blood drops below normal (which can be very dangerous if the patient loses consciousness), was viewed as an essential barrier for both doctors and patients. During my time in Novo Nordisk, the moment of 'insulin initiation' received special attention interest and seemed to represent the moment where the barriers fell.

In Oticon, there was a great interest in the process that people go through on their way to becoming 'first-time-users'. This process, the end-user-journey, involves the acceptance of hearing loss and the search for medical help (Oticon 2014). The end-user-journey comprises several stages where the potential user first becomes aware of his or her medical condition and then seeks information and medical assistance for it (see page 32). According to one study, 40% stop the journey after their first visit to an ear, nose and throat doctor, suggesting that something in the clinical encounter had not been done well (Meis and Gabriel 2006). Other barriers that were brought forward in studies and presentations within the organization included the patient's negative expectations about the device[1]. Users were concerned that hearing aids could be uncomfortable, difficult to use, and not restore natural hearing. Some people did not believe that their hearing loss was severe enough to need amplification. It was also often mentioned that a stigma was attached to wearing hearing aids and that some people wanted to avoid them because of their associations with old age, disability and deafness (see also Arnold and Mackenzie 1998). Lastly, national health insurance in some countries did not cover hearing aids, and the cost was also considered a barrier for purchase. While I was working in Oticon, I was introduced to the concept of 'readiness management' that made the health care professional responsible for appropriately guiding the patient along the journey of towards readiness to start using hearing aids (Schum et al. 2012).

My colleagues in the two companies thus shared an empirical interest in the clinical encounters, where potential users meet a healthcare professional and an analytical interest in

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[1] Studies conducted by European Hearing Instrument Manufacturers Association and Better Hearing were important source s about potential costumers' attitudes (Hougaard and Ruf 2011; Kochkin 2005; Kochkin 2009).

doctors' and patients' reluctance or lack of readiness to start treatment. These interests made an important starting point for my research. My task was to produce a taxonomy of barriers to treatment, and to analyse situations in which barriers surfaced. In the research group we soon decided to make the clinical encounter the empirical focal point. However, I was puzzled by two assumptions that seemed to underpin the companies' understanding of their potential users.

The first assumption was that people move on a trajectory towards use, but are hindered in their progression by 'barriers'. It raises a need to explain the lack of movement and the barriers to an otherwise rational progression towards use of the treatment devices. In the research for my MA thesis on clinical interaction in general practice, I was inspired by a pragmatic approach and found that treatment plans were situated in particular circumstances and guided by diverse and practical rationalities (Mattingly 1998). In my doctoral research, I therefore turned my analytical interest from the vocabulary of barriers to an exploration of the rationality inherent in social interactions across settings in which the conditions were related and reacted to.

The other assumption that puzzled me was the understanding of the clinical encounter and preferably the moment of 'initiation' (in Novo Nordisk) or 'purchase and fitting' (in Oticon) as a pristine moment of importance. It seemed to reflect what Mol calls a 'logic of choice', in which the patient is a consumer making a choice of use or non-use. According to this logic a product changes hands in a clearly defined transaction, confined to specific moments (Mol 2008:20,54). Mol argues that diabetes care is better understood by a 'logic of care' and as an 'open-ended process that may be shaped and reshaped' (ibid.). I had reservations about being able to understand this process from observations of standalone clinical encounters, and I believed that the process stretched from the clinical setting and into the home.

At this point, a few months into the project, the object of study started to take form. The clinical interaction was the focal point, not as pristine moment of choice in which barriers to treatment were overcome, but as a site for dealing with hearing loss and diabetes.

Anthropology *with* design

Another relation that shaped my object of study was the relation to design. My design colleague, Janet, and I worked together throughout the project, within the same framework, but with parallel objectives. Mine was to understand practices of handling conditions in relation to treatment options. Hers was to explore the ways in which pre-users can contribute to design and innovation processes. It was our shared interest to understand current practices of handling hearing loss and diabetes; to scrutinize current and possible relations between persons and treatment technologies.

Historically, the relationship between design and anthropology has mainly been through ethnography. Ethnographic methods have helped design to better understand needs and experiences of users as well as the context of use (Otto and Smith 2013:2), and presented a promise of informing designers about ‘the real world’ (Crabtree 2004).

In the field of anthropology this use of ethnographic methods caused critique. When people outside the social sciences use ethnographic methods, they might be able to describe the world, but risk reducing anthropology to mere data collection and not arriving at an anthropological understanding of the complexity of human interactions (Vangkilde and Jöhncke 2009). A risk of such ‘scenic fieldwork’ as Button calls it, is that ‘fieldwork that merely describes what relevant persons do may well be missing out on the constitutive practices of *how* they do what they do, the ‘interactional what’ of their complexes of action’ (Button 2000:329, authors emphasis). Moving from a simple depiction of what is to be seen, to a study of *how* these activities become meaningful in a particular setting, allows for a richer understanding of social interaction. A consequence that Button draws from this observation is that designers should not be trained in analytical methods of social sciences, and that a division of labour between designer and analyst is in order to ensure a proper understanding of social interactions before proceeding to intervention (2000:330).

However, such a division of labour raises the problem of relating the analytical understanding to relevant design problems. What may happen is that ethnographic studies are summed up in generalizable recommendations as ‘implications for design’ (Crabtree 2004). While a division of labour ensures the ethnographic attention to the complexity of social interaction, it also places the task of identifying potentialities for design on the ethnographer. The division of labour creates a gulf between ethnography as a *descriptive* and analytical practice and design as a *prescriptive* practice (Halse 2008).

More recently design anthropology has evolved into an emerging field of its own, a ‘distinct style of knowing’ (Otto and Smith 2013). Anthropology working *for* design by conducting fieldwork in the service of design (Gunn and Donovan 2012), has been accompanied by anthropological studies *of* design, where the practices, specificities and limitations of design is made an object for anthropology, and by anthropology *as* design, using design’s collaborative, creative and intervening methods as a model for anthropology’s future (Suchman 2011:3, Murphy and Marcus 2013:261). In contrast to these anthropologies *of*, *for* and *as* design, Gunn has suggested that truly working *with* other disciplines involves a movement along an integrated path, where practitioners are engaged with and learn from each other (Gunn 2008). Conducting anthropology *with* design entails that researchers aim to achieve a processual understanding and are dedicated ‘not so much to the achievement of a final synthesis as the opening up lines of inquiry’ (Gunn and Donovan 2012:9). The collaboration between anthropology and design, Janet and I conducted, was characterized precisely by learning from each other and continuously opening up lines of inquiry.

Since it was just the two of us making up the research team a close collaboration seemed to be a natural point of departure as well as a way of creating continuity as we moved between companies, field sites, disease areas and countries. However, some division of labour still appeared to be in place, and since we each had our competences and experiences from our own fields, I was responsible for setting up and facilitating the ethnographic research, while Janet was responsible for the design of concepts and for setting up workshops. At the same time, we would always run interview guides and design concepts by each other, and Janet took part in many of the field activities, just as I co-facilitated and assisted in the design workshops. However, the impact of our collaboration goes far beyond practical assistance. Our ambition of engaging with each other’s disciplines and knowledge practices had important consequences for the movement from empirical material to analytical conceptualizations in a way that did not simply bridge the descriptive ethnography with a prescriptive design, but engaged us in the mutual objective of exploring existing and possible relations between health conditions and treatments (Halse 2008, Gunn and Donovan 2012).

As we started our first months of fieldwork, we also discussed what we saw and heard from our informants. Had I been conducting a traditional anthropological study, these analytical thoughts would probably just have remained in my notebooks. Being engaged with design meant that Janet was already searching for design interventions, while the fieldwork was ongoing. This pushed us to identify themes in our ethnographic material very early in the process. As a consequence, analytical themes were articulated and have been running through the project in diverse forms of design activities as well as guiding our attention in the fieldwork. As a theme was developed we experimented with designing for it and inquiring it further in our ethnographic field. One such theme that kept appearing in my notes and our conversations was the apparent invisibility of the chronic condition, and how it was handled. During fieldwork we often noticed that people in the early stages of hearing loss and diabetes found their conditions to be capricious, possibly progressive yet sometimes hardly noticeable. The measurement provided medical evidence of the condition; the truth about their disease. However, we soon found that the test results and numbers were subject to negotiation and interpretation. They were rendered meaningful by being related to sensory experiences and past events. When we moved beyond the clinic, people had other methods for assessing the stage of their conditions. These kinds of observations inspired further ethnographic exploration into the emergence of medical conditions through practical inquiries. At the same time they formed the ground for critical design interventions that were conducted in workshops throughout the project (see Kelly 2014 for a thorough description of the design methods)[2]. There was a constant back and forth between ethnography, conceptualizations and interventions (the analytical work is described in further detail below).

Anthropology's affinity with ethnomethodology

With the 'Innovating with pre-users of medical devices' the SPIRE Research Centre had a particular interest in analysis of 'structures of action as observable and describable through naturally occurring interaction collected in medical settings' (the original project description). This interest was situated in the field of conversation analysis, a branch of ethnomethodology developed by Harvey Sacks in collaboration with Emanuel Schegloff and Gail Jefferson, committed to viewing talk-in-interaction as a constitutive activity, and proceeding through detailed analysis of recorded interactions (Gubrium and Holstein 1997, Maynard and Clayman 2003:176). Conversation analysis has a special interest in how orderly characteristics of talk 'are accountably produced by interactants via procedures implemented on a turn-by-turn basis' (Maynard and Clayman 2003). This analytical approach is rendered possible by detailed transcriptions of video recordings of naturally occurring interactions. As we started our fieldwork only a few months into the project, the bringing together of the two traditions, ethnomethodology and anthropology, became a practical matter of combining field methods rather than examining and comparing philosophical assumptions. In the following pages, I will describe the methodological problems that emerged during fieldwork, and draw on the literature to discuss how I solved them (for extended discussions of the affinity between ethnography and ethnomethodology, see Pollner and Emerson 2001, Gubrium and Holstein 1997)

Recording naturally occurring interactions

My fieldwork for my MA thesis had familiarised me with making video recordings of clinical encounters, which had been useful in allowing me to revisit my data, discovering new details I might not have been looking for at the outset of my fieldwork. My company supervisors were also in favour of recordings, as the recordings generated material for the dissemination of our findings within the companies. It seemed obvious to combine the two complementary methodologies to ensure an abundance of well-documented empirical material, and I prepared to combine

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[2] Writing up, I often considered including the design workshops in my ethnographic material for a richer material. However, I chose not to. The ethnographic material I had, covered two disease areas and two countries and a number of different sites and was already enough for one thesis. Another reason for keeping focus on my ethnography was that the task I was given was to understand the current situation, and not how possible interventions might alter it. In contrast, Janet focused on the design methods (Kelly 2014).

participatory observations throughout the everyday activities in the clinics with recordings of the clinical encounters.

In practical terms, the combination went fine. I spent entire days in the clinics, following the doctors and brought out the camera whenever a patient with diabetes or hearing loss agreed to participate in my research. However, the two methodologies soon started to appear incongruent. Where anthropology seeks to understand the everyday life by taking part in it, on the premises of this social life, and thus observing from a situated position (Tjørnhøj-Thomsen 2003:94), conversation analysis is interested in members' interactions amongst and for themselves, and not in relation to an outside researcher (Pollner and Emerson 2001). The aim of recording undisturbed, naturally occurring interactions seemed to ignore the processes and relations in and through which knowledge is produced. In anthropology these processes are considered fundamental to the relational knowledge production of ethnography (Hastrup 2003b). In the field of conversation analysis, the recordings are often referred to as 'the data', as if they were pristine and objectively existing entities, not the result of a situated practice. Through the practices of treating video recordings as separate entities, they are ascribed a knowledge status very different from field notes, not to mention handwritten 'scratch notes' or the continuously evolving and changing 'head notes' (Sanjek 1990). It appeared to me that the presence of a researcher could be ignored, as if the camera was not placed in the clinic by someone and with a particular purpose. My attempt to combine ethnomethodology with anthropology was thus not unproblematic. However, as the project evolved, these points of incongruence became important sources of analytical inspiration and sensitivity to methodological issues[3].

On the one hand my anthropological sensitivity to situatedness of ethnography affected the way I handled my recordings. In most cases the camera was treated as fairly unproblematic by both doctors and patients; once I had introduced the purpose of my research and the patient had signed the consent, they concentrated on their clinical encounter. There were, though, times where the process was not seamless. In one case a doctor and his diabetes patient repeatedly promised to talk about lifestyle issues in their next appointment, and not today as if today was different

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[3] An important experience for the development of my methodological stance happened during my stay in New York City, where I joined the research group 'Language and Social Interaction' (LANSI) at Columbia University. Here I met Clemente, who worked in both conversation analysis and anthropology. His solution to the apparent incongruence of the methodologies was to make two parallel analysis of his field material. He juxtaposed the two analyses without combining them (Clemente 2012:698). With the number of divisions I already had in my material, the outlook of having two analytical strategies run in parallel did not seem appealing. When I later attended the conference 'Curiosity and Serendipity' in Lund 2012, I heard Gubrium talk about 'ethnomethodologically informed ethnography', and became inspired by this mutual affinity of ethnomethodology and ethnography (e.g. Gubrium and Holstein 1997). I gave up combining Conversation Analysis with anthropology in favor of combining it with this alternate branch of ethnomethodology.

because I was there recording them. My presence in the room made me more sensitive to the ways in which doctors and patients related to the camera.

At the same time, the video recording proved valuable in permitting me a repeated and detailed examination of talk and embodied practices (see Goodwin 1994:607). As we shall see in chapter three, the recordings allowed me to observe the skilful and dynamic work through which doctors and patients collaboratively produced the body as an object for medical practice and made sense of its ailments. The video enabled me to observe the details of the interactions and relations through which this meaning-making work is accomplished. Methodologically, my familiarity with 'naturally occurring interactions' made me more attentive to the interactional and interpretive skills of my informants.

The privileging of interactions seemed problematic for the practice of interviewing. It was my idea to supplement the recordings of clinical interactions with interviews in the homes of the patients. I wanted to learn more about their experiences and lives with the conditions than was imparted in a brief consultation. However, these conversations were not a natural part of their everyday lives. Some ethnomethodologists pose the critique that accounts elicited through interviews depict a determinacy that the events did not possess when they were lived and experienced (Pollner and Emerson 2001:119). In light of this critique, it is not the interview that is problematic, but how it is treated. Ethnomethodologists do not analyse people's descriptions as reports, but as events taking place in a particular setting (Gubrium and Holstein 1997:54). This approach to the interview is not unfamiliar to anthropology, and as Michael Jackson points out, retelling one's experience is a reconstruction of the past, taking place in a present in relation to other people (Jackson in Dalsgaard 2004:53). Ethnomethodology drew my attention to the way in which the interview is a situated account, taking place in a particular context. (I will follow up on this issue, as I discuss the interview in the methods section below.)

The problem of context

The notion of context was another point of difficulty in my encounter with ethnomethodology. In anthropology, the conventional understanding of context is that anthropologists draw on the features surrounding a phenomenon to understand and give sense to it (Dilley 1999). This approach to context is problematic in ethnomethodology, which holds that only members, not researchers, give sense to a phenomenon. In ethnomethodology, context is confined to that which 'members of society are themselves oriented to, and which they invoke in their social interaction with each other, rather than as something the sociologist invokes by theoretical fiat' (Francis and Hester 2004:19). In other words, the intelligibility of talk and actions depends on and influences the ongoing sequence of interaction (Maynard 2006). From this viewpoint, context is produced by members in interaction; it is both constitutive for and the outcome of the interaction (Dilley 1999:19). This understanding of context reflects a central understanding in ethnomethodology: that social interaction is 'reflexive', meaning that situations simultaneously emerge from and form the basis of social interaction (Gubrium and Holstein 2003:25)

When I started my ethnographic research, I was already following the recommendation to look for participants' own way of deciphering their world. At the same time I believed that I, by collecting, selectively representing and assembling elements from my empirical material, relating it to the literature, discussing it with colleagues and writing a thesis about it, created an understanding different from that of the participants in the interaction (Hastrup 2003a). This encouraged me to rethink the notion of context[4]. As Roy Dilley demonstrates, social anthropologists use the concept of context in a variety of ways. One particularly useful way of understanding context in my project is as a matter of making connections, and consequently disconnections (1999). Dilley suggests that 'contexts are sets of connections construed as relevant to someone, something or to a particular problem' (1999:2). Making connections is thus an interested activity in which certain relations are made, while others are deemed irrelevant. In bringing about my empirical material I connected sites where relations between the body, disease and treatment were enacted. My methodology was built on the assumption that I would understand clinical encounters better by spending more time in the clinics, taking part in other everyday activities and by relating those to the practices of handling diseases in the homes.

From an ethnomethodological point of view, only the connections made by participants of social interactions are relevant to its intelligibility. It is not the researcher's task to make further connections and create meaning beyond what is locally emerging. This builds on the understanding that all social interaction is meaningful and orderly in itself, and should not be explained with rules or norms by the researcher (e.g. Pollner and Emerson 2001).

The two positions appeared to be contradictory. However, I wanted to include ethnomethodology's critique in the ethnographic project in order to lend it a greater methodological sensitivity. Gubrium and Holstein argue for a mutual affinity between ethnography and ethnomethodology (1997). Like Pollner, they advise us never to replace a member's understandings with our own, but at the same time observe that we may displace these understandings across the landscape of mundane reason. In other words, making *connections*

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[4] In *Linguistic Anthropology*, Alessandro Duranti discusses anthropology's critique of conversation analysis' disinterest in context (1997:264ff). He breaks the critique into three components: 1) a disinterest in the 'larger context'; when and where the exchanges take place, 2) a rudimentary notion of what constitutes speech (the transcript will always differ from the conversation), 3) a disregard for participants' own interpretations of their behavior (they are often not aware of their own speech behavior and would explain conversations differently) (ibid:266).

between different sites where meaning is produced may render the partiality and situational differences of each site visible (Gubrium and Holstein 2012:95). Gubrium and Holstein also suggest that, while ethnomethodology usually is exclusively concerned with *how* people render the world meaningful, understanding *what* is at stake for people demands attention as well (2012:96). Exactly these two aspects of what lies beyond the moment-to-moment interactions will be included in my analysis; I will connect different sites where diabetes and hearing loss are meaningfully enacted (in line with the multi-sited ethnography discussed above), and I will be interested in people's concerns and regard their actions as directed towards an objective (in line with my discussion of 'directed action' in chapter one). The displacement across sites is reflected in the movement between each of my analytical chapters from one setting or moment to another, from the clinic to the home, and from there to the companies. As we will see in chapter four, it is crucial for my analysis to understand what concerns people have.

Analytically, ethnomethodology has created an awareness of how to use contextualizations, not as ways of explaining a phenomenon with something that lies beyond it (e.g. rules or norms)[5], but rather as a way of situating interactions. A consequence of this interpretation of context is that I do not make sense of the local interactions I observe, by placing them within a larger picture, such as the political landscape of health care policies or the commercial landscape of market mechanisms. Instead, I make connections between different sites, and thereby draw a picture of the field within which I work. The sites I focus on and the connections I make (and disconnection from the 'larger picture') are selected as sites of interest to the companies, with a possibility for design to intervene and from my methodological stance in pragmatism and ethnography.

THE TREATMENT LANDSCAPES

A fundamental feature 'given' with the initial framing of the project was the assumed similarity between diabetes and hearing loss that established a shared ground for the study and the companies' interests in 'pre-users'. Both hearing impairment and type 2 diabetes are progressive,

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[5] A classic example of the ethnomethodological reframing of norms from a device for explaining events of conduct to devices whereby the sense of events are socially constituted, is Weider's study of the convict code in a halfway house (Weider 1969). In the first part of his thesis, he describes the patterns of resident deviance and rule violation that undermine the efforts of the staff. In the second part, he provides an alternate, ethnomethodological approach and analyses the telling of the code as a constitutive activity; the code is not seen as determining deviant behavior, but used to constitute what is deviant (see also Gubrium and Holstein 1997:45-52).This distinction between seeing rules and norms as governing action or as constitutive of it, is often used in differentiating between traditional ethnography and ethnomethodology; ethnography as explaining behavior with social norms, while ethnomethodology is interested in how the norms are used (e.g. Jimerson and Oware 2006). However, in much recent anthropology, particularly in the field inspired by pragmatism there is a similar interest in how people *use* norms as resources in handling problematic situations (e.g. Whyte 1998; Whyte 2004).

chronic conditions that cannot be cured, but may be ameliorated with treatment technologies. In both cases, many people do not start treatment early enough for it to be most beneficial for them. The relation to health care professionals is also comparable, since the patient in both cases needs to see a professional at least once prior to the initiation of treatment, and as mentioned earlier, the clinical encounter was of great interest to both companies. The main part of the fieldwork took place in Denmark, supplemented with three months in the United States of America. This too was ‘given’ with the project, since North America comprises the largest market for both companies and they wanted to be certain that our results would be applicable beyond the limited Danish market. The following is an account of how I related with the two conditions and countries as I conducted my fieldwork, and how I became aware of the other differences and similarities that have structured my work. At the same time, the account situates doctors and patients within the treatment landscapes.

An early observation during the field research was the different ways in which the two health conditions surfaced as problematic. The problem of hearing impairment emerged in relation to other people when communication was disrupted. However, that meant that most people I met, did fine in many situations – as in our face-to-face conversations, often in a quiet living room. Hearing impairment surfaced only in particular circumstances, and as Engelund has observed it is a matter of gradually becoming aware through repeated disruptions and their social and emotional impact (2002). Diabetes, in contrast, was imperceptible to most people I met; they did not feel the fluctuations in their blood sugars and in many cases their diagnoses had been given as a consequence of some general blood test, rather than a consequence of symptoms. Whereas the people with hearing loss were in a process of inquiring into and dealing with the emerging impairment, people with diabetes rarely questioned the diagnosis, but were weighing the risks of future health complications.

This distinction made for two quite different treatment courses. People with diabetes were often engaged in long courses of treatment with regular medical visits before starting insulin treatment. In both Denmark and USA, diabetes is closely monitored, and is a much-researched disease, for which the guidelines often are revised. The doctors I met in both countries followed guidelines that were based on the same international recommendations[6]. These suggest that a patient with type 2 diabetes be seen by a health care professional two to four times per year, and for an annual and more thorough review visit by a medical doctor. The purpose of the review

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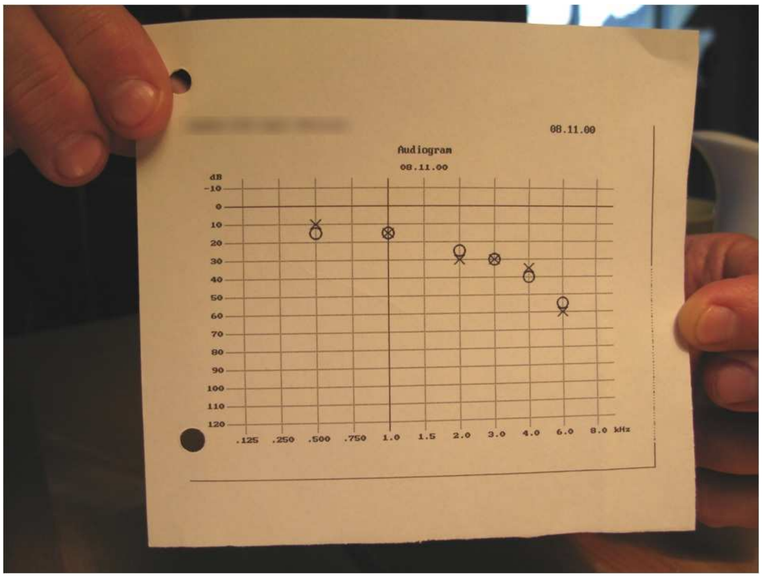
[6] The International Diabetes Federation makes international guidelines, while national versions are developed by Danish College of General Practitioners and American Diabetes Association amongst others. The general recommendations are the same, while it is observed that there are disagreements about the use of particular drugs (Danish College of General Practitioners 2012).



A research participant holds up his audiogram that shows a loss in the high frequencies.

visits is to encourage lifestyle changes and to regulate hyperglycemia as well as other risk factors, including weight, blood pressure and cholesterol, in order to prevent complications (Danish College of General Practitioners 2012). An important measure in the treatment is the blood glucose level. Two tests are often used in these clinical encounters. The long-term blood sugar test (HbA1c) allows the doctor to see an average of the blood glucose over the past three months. For some years blood sugar values were treated down to an HbA1c at 6.5%, but the most recent recommendation is to set individual treatment goals, and allows for a variation from 6.5 to 7.5% for the majority of patients[7]. During the review visit, this test was often supplemented with a short-term test (fasting blood glucose) that shows a picture of the here-and-now. In Denmark this test is measured in mmol/l and in US in mg/dl, and should preferably stay within the range of 70 mg/dl (3.9 mmol/l) to 180 mg/dl (10.0 mmol/l) during the day, as it will peak after meals (American Diabetes Association 2014). Apart from visits at the general physician, the patient will also need to see a podiatrist and an ophthalmologist on a regular basis. If there is deterioration of the nerves or small vessels, early symptoms include vision changes and numbness in the feet. Some patients are also seen by a dietician; in Denmark they may be referred to a course for diabetics, where they are taught about medical treatment in addition to diet and exercise. The series of visits means that the patients and their professionals come to know each other quite well. From the consultations I saw, it was clear that some doctors were familiar with their patients'

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[7] Since I conducted my fieldwork the standard measure has been changed from % to mmol/mol in the newest guidelines. However, since blood glucose levels are measured in % in my empirical material, I stick to the old standard.

lives and struggles, and many patients I talked to said that being able to trust their doctor was crucial. Several of them had changed doctors before finding one with whom they had a good collaboration. People with hearing impairment had more intermittent contact with their health care professional before becoming users of hearing aids. The practitioners I met did not follow any formal guidelines for review visits, and the patients I met often waited several years before going back. In Denmark, the patient needs to see a doctor to obtain a referral and reimbursement of the cost of the aids, but may then purchase the hearing aids from either a private audiology clinic or a public hospital. In the USA, insurance generally does not cover the costs, and the patient may go directly to an audiology clinic or one of the clinics where ear, nose and throat doctors also dispense hearing aids. The most common hearing test is pure tone audiometry. The test is made with pure tones of discrete frequencies, and the hearing threshold, the softest sound (measured in dB) that the patient is able to perceive is determined. The test is carried out for the left and right ear separately, and the result is plotted onto an audiogram – the threshold of the right ear is marked with circles, and that of the left is marked with crosses (Elberling and Worsoe 2006). In the picture, an informant shows his audiogram. The frequencies increase from left to right, and the sound level increases downwards; the lower the mark, the higher the volume is needed to make the sound audible. This audiogram shows a loss in the higher frequencies in both ears. Hearing loss is usually rated as mild, moderate, severe and profound. There are no exact definitions, but according to Elberling and Worsoe, a mild loss ranges from 10 to 35 dB, a moderate loss from 35 to 70 dB, and severe and profound are between 70 and 100 dB and 90 and100 dB, respectively (2006).

The differences in monitoring of the conditions reflected the potential dangers. Poorly regulated diabetes can be fatal, so close monitoring and treatment are essential in the clinical practice. Between review visits, the patient is responsible for taking care of his/ her diabetes and ascribed responsibility for following treatment recommendations, and living healthily. Type 2 diabetes is a widespread disease whose prevalence is rapidly increasing. The tendency during my fieldwork was increased control, not only with the patients, but also with the doctors through a program called DAK-E installed on computers in general practice to register data on diabetes patients (amongst others) and send it to a central database (Danish Quality Unit of General Practice 2014) in the hope of improving the quality of treatment. Some doctors I met told me that diabetes care had received a great deal of political attention and strong patient organizations argue their case, and some doctors said that diabetes care had been prioritized at the cost of other disease areas. A tendency in many clinics was to hire a nurse to take care of the review visits of type 2 diabetes, hypertension and other chronic conditions.

In hearing care, on the other hand, the progression of impairment was not associated with danger, but with inconvenience. The patient was rarely held responsible for the degradation of his or her hearing, but to a large extent given the right to decide if treatment was needed. In Denmark, however, hearing care has also been influenced by a debate in the media over the reimbursement for expensive hearing aids; some doctors saw it as their responsibility to regulate the amount of public resources spent on hearing instruments. In the USA, this problem did not exist. However, some of the doctors and audiologists I met were careful not to push patients to start treatment, if they were not interested, and one person said she did not want to be perceived as trying to sell expensive devices to people who would not benefit from them.

While the similarities between the conditions were the point of departure, juxtaposing them became my analytical strategy for articulating the reality constructing practices in each disease area. Even though there are significant differences between the two countries and not least their health care systems, the resemblances of the everyday practices of dealing with hearing loss and diabetes were more striking than the differences, and I decided to treat my ethnographic material as an empirical whole within a Euro-American setting rather than exploring cultural differences across national borders.

THE METHODS

In the following pages, I will turn to the ethnographic methods by which my empirical material has been brought about. My ethnographic path has branched out into a multitude of sites. Getting into the field, was not so much a matter of settling in an unfamiliar setting, but rather a matter of ongoing movement between multiple sites, from medical clinics, to private homes and with the two companies as my base. Following Marcus' argument for multi-sited field research (1995), the sites are connected as different locations for dealing with either hearing loss or diabetes. My displacement between them rendered visible the mundane practices and situational differences of each site (Gubrium and Holstein 2012:95). Methodologically, each site provided its own set of possibilities for observing practices, taking part or asking questions.

Locating and accessing the field

Even though I soon abandoned thinking of 'pre-users' as people on a determined trajectory to use, the concept has shaped the object of study. The narrow definition of these people by their possible future relation to a product was displaced by a much more complex set of relations and interactions. The empirical focal point for our study was the clinical encounter. Through ongoing 'location work', this 'given' site was altered and extended in several ways (Gupta and Ferguson

1997). First of all, I decided to look not only for moments of initiation of treatment. As I pointed out earlier, care of chronic conditions is an ongoing process, where the onset of use of a treatment device does not take place at one single point in time, conceptualized as a ‘choice’ or ‘handing over of a product’ (Mol 2008). With this perspective in mind, I was not only looking for consultations where choices were made to start or not start using hearing aids or insulin, but more broadly for consultations in which the diseases were examined and treatment plans discussed. Secondly, I knew from my previous fieldwork in medical clinics that there is much to be learned from spending time in the clinics beyond the clinical encounter. Staying all day in the clinic made it possible for me to talk to the doctors when they were between patients, get an impression of the variety of health care issues they were treating, converse with the clinical staff over lunch and sit in the waiting room to see and hear what incoming patients saw and heard. Thirdly, I wanted to move beyond the clinical setting to understand what it was like to live with a hearing impairment or diabetes. Finally, while writing the thesis, I returned to the companies as yet another location where relations between health conditions and their treatments are enacted, to link my own work to their reactions. The work of locating practices to be part of the object of study was an ongoing process of interacting with other people involved, drawing on my earlier field experience, informed by readings of the literature in medical ethnography, shaped by what I serendipitously learned in the field and even continuing as I was sitting at my desk, writing up my thesis.

We started the research project in August 2009, and after the first five months, including two months of fieldwork, I put the project on hold while I took maternity leave (and while Janet worked on another project for Novo Nordisk). We resumed the project in November 2010; we were back in the field early 2011, and completed our last observations and interviews in Denmark in July 2011. While wrapping up our fieldwork in Denmark we were already busy planning the next phase of fieldwork in USA. We spent three months in New York City in the autumn of 2011. The aims of the two blocks of research were slightly different: the objective of our fieldwork in Denmark was to explore the practices of handling the conditions, and our objective in the USA was to build on what we had learned in Denmark. Rather than gathering a similar set of data to make a comparison between the two countries, we wanted to investigate current analytical themes in greater detail.

Access to clinics

The reason for studying clinical interaction was to understand what kept people from becoming users. For this reason, the companies were interested in a study of clinics that represented the early encounter for the patient. In the case of diabetes care, the best sites for such a study were the offices of general practitioners, since this is where the ongoing care of diabetes takes place, even if an endocrinologist initiates the insulin treatment. In the field of hearing care, the ear, nose and throat doctor similarly constitutes an early point of contact for many patients, though it is more often an audiologist who introduces a new user to the hearing aids. Oticon had an interest in understanding why so many people leave the ‘user journey’ after their initial visit to the ear, nose and throat doctor.

Planning the fieldwork was a matter of balancing depth with breadth. From an ethnographic perspective, I wanted to spend enough time in the clinics to get an impression of what everyday life was like. To gain credibility as a study of the companies’ potential markets, we needed some degree of variation across clinics and doctors, so that our data were not particular to a single doctor’s personal style. For these reasons we aimed to visit three clinics of each kind for three days.

With the decision about combining video with other ethnographic methods, my immediate concern was to find doctors who would be interested in participating in our research, having us in the clinic and allowing us to video record their interactions with patients. When I did fieldwork for my MA, I spent several months in a clinic, before I brought the camera out and recorded consultations, and I found that it took a certain degree of trust before I asked the doctors permission to record. In my search for research participants, I decided to take one step at a time, and give doctors every opportunity to decline participation, so that I would be observing and recording only the doctors who were comfortable with my presence and that of the video camera. I sent letters to more than 100 doctors in the greater Copenhagen area with a brief presentation of our project, asking if they would be interested in a first meeting, and optionally decide if they wished to participate in the following part of the research, including observations and video recordings. At first the method seemed to work very well, and in the autumn 2009 I quickly found two doctors who opened their doors to me: one ear, nose and throat doctor and one general practitioner. When we looked for more clinics in 2011, the process was a little more prolonged. I ended up talking to nine general practitioners before I gained access to three clinics and four doctors. The clinics ranged in size, from one to eight doctors; all were in the greater Copenhagen area. I received fewer replies from ear, nose and throat doctors, and only two were interested in participating, so I used my personal network to find a third clinic. The doctors who agreed to take part were extremely welcoming and helpful with finding patients. Some of the clinics I came to know quite well from coming back several times, and one clinic was the same place in which I had spent several months conducting research for my MA thesis in 2006.

When Janet and I started planning our trip to New York, we had learned that accessing clinics would be time-consuming and difficult, so we started arranging contacts well before we left

Denmark. Because of the distance, we used our contacts in the companies to gain this access. An employee from the Oticon headquarters in New Jersey put us in contact with clinics that were clients. Taking part in our study was a favour the clinics did for Oticon and possibly to build a better relation with them. In Novo Nordisk there was a standard procedure for recruiting study participants, and all contacts were arranged through an agency. As a consequence we had more of a business relationship; they were paid for their participation and made every effort to make sure we received the data we needed for our study, even allowing us to video record and scheduling extra patients on the days we were there.

Access to homes

My initial idea had been to follow the patients as they moved from one context to another, but that soon appeared to be a challenge. Arranging access to the clinics was a matter of waiting, and taking one step at a time, and hoping to meet patients in their clinics, who would take part in our research, seemed to be a long shot. In my entire material across the two countries I met two persons in the clinics, whom I interviewed in their homes, and another two whom I accompanied on a consultation with their doctor after the interview. Most of our informants were found through snow-balling, notices on the company intranets, posters in a health care center near Copenhagen, and an announcement on the webpage of the Center for Hearing and Communication in New York. The diabetes patients we spoke to in New York were recruited by the agency Novo Nordisk used. Rather than following certain people or things moving between sites, I moved between places where practices and experiences of dealing with the conditions took place.

Most of the people we involved in our research on hearing impairment had an acquired mild or moderate hearing loss. Most of them had had their hearing tested, and only a few had not seen a health care professional yet, but noticed that their hearing was not as good as it had been. All of our participants with diabetes had been diagnosed but had not yet started insulin treatment. Some of them used injection devices to administer other anti-diabetic medication[8], and all of them were receiving some kind of treatment. We started out hoping to visit eight people with each condition in Denmark and four of each in the USA (the actual numbers can be seen in the table on page 50). The design workshops were conducted with participants we had already interviewed.

As I made my way into the field, many interesting opportunities presented themselves, only some of which I had time to explore. In Copenhagen, I asked at several public health centers if I could put up my poster, and in one case a kind nurse sat down and told me about diabetes treatment and invited me to sit in on their course. I took part in cooking and exercise classes. In

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[8] All the informants who injected were having GLP1, a relatively new product (the first to be launched was Byetta by Eli Lilly in 2005 in the USA). GLP1 stimulates the release of insulin and inhibits the release of glucagon. GLIP also delays the uptake of glucose from the intestines (Christiansen 2014b).

another case, I met a doctor who shared our interest in user involvement and we collaborated on a workshop. In New York, we visited the Centre for Hearing and Communication and learned about their advanced ways of testing hearing. Besides the planned field activities, I learned a great deal about my field from these serendipitous openings.

In the clinics

In both disease areas, we studied health care professionals who worked with a much broader range of health care issues. The consultations on hearing loss or diabetes could be few and were often scattered throughout the day[9]. In many cases, the doctors were helpful and tried to schedule as many patients with hearing impairments or diabetes in a day as they could, and I planned my days in the clinics accordingly.

The shift of focus from the moment of choice to the handling of diabetes and hearing impairment before the medical device was introduced, meant that I observed a range of ways of reaching a 'situation of choice' (Mol 2008) and of orienting to the diseases in need of treatment. With regards to hearing loss, I observed patients who came in for the first time with hearing difficulties; others had come in several years earlier, and quite a few had a hearing test as part of their ear, nose and throat exam when they came in with issues like dizziness or tinnitus, not because they were concerned about their hearing. My presence in the clinic throughout the day, made it possible to sit in on consultations that had not been pre-scheduled as 'hearing impairment', but that were tangential to it. With regards to diabetes, I observed review visits with patients at all stages of their condition; some were newly diagnosed, others had had the condition for years, some were well-regulated and others were still struggling to reach their treatment goals. I thus came to see different ways of relating to the diseases as part of ongoing course of treatment, not only the patients on the brink of starting insulin treatment or hearing aids.

I also sat in on many consultations that pertained to neither hearing loss nor to diabetes, and that did not in themselves form part of my empirical material, but broadened my understanding of it. Both general practitioners and ear, nose and throat doctors see a lot of patients on a normal workday, and shift between a myriad of disease areas as well as between acute health issues and ongoing care. In the clinic of one ear, nose and throat doctor I observed a lot of parents coming in with young children, and noticed how the doctor prepared the physical examination by letting the

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[9] We could have chosen other sites where treatment initiation takes place much more frequently, as audiological and endocrinological departments in hospitals. However, we did not want to study how patients are taught to use the devices once they have been referred to treatment, but rather understand what happens before that.

	HEARING LOSS	DIABETES
DENMARK	**Three ear, nose and throat clinics** 30 consultations (no follow-up interviews) **In their private homes** Seven people interviewed 1-2 times	**Five general practice clinics** 23 consultations 7 follow-up interviews **In their private homes** Seven people interviewed 1-2 times
USA	**One ear, nose and throat doctor and one audiology clinic** 7 consultations 8 follow up interviews in the clinic **In their private homes** Three people interviewed twice	**Two general practice clinics** 14 consultations 14 follow up interviews in the clinic **In their private homes** Four people interviewed twice
TOTAL	12 clinics 74 consultations 29 follow-up interviews in the clinic 21 people visited in their homes 15 recorded interviews with health care professionals	

Overview of recorded empirical material from clinics and private homes.

hard surface of the stethoscope or otoscope touch the child's arm while explaining what was about to happen, before looking in the ear or placing a stethoscope on the chest. Seeing thistangible practice made me curious about the techniques for preparing treatment with adults. In some cases, I observed doctors who would bring out the hearing aid or insulin pen for the patient to see and hold, and I also saw different ways of explaining how to use them, as I will show in chapter five. As I became more acquainted with the doctors' work, I decided to focus on hearing loss and diabetes, not on everyday life in the clinic. As a consequence, I conducted brief follow-up interviews with the patients rather than following the doctors through all consultations.

Being in the clinic all day also taught me about how doctors linked hearing loss or diabetes to other diseases. One ear, nose and throat doctor said he did not believe that he could make a great difference with hearing aids. He compared hearing care to a surgery he had done on a patient with a crooked nasal septum. The surgery restored the nasal septum to normal, so that the patient could once again breathe comfortable through the nose. Hearing aids do not restore hearing to normal, he said, and they are difficult to use. The nasal septum repair could restore the physical functioning of the body, but treating hearing impairment required different skills that pertained to talking to the patient and teaching about the aids. Some of the doctors enjoyed this communicative challenge, but others preferred to treat conditions that could be corrected in the operating room.

Diabetes care in general practice was characterized by frequent review visits. Compared to acute diseases where a consultation could include both diagnosis and treatment without any scheduled follow-up visits, diabetes care was an ongoing process, where many treatments were tried out and adjusted. I saw doctors ask their patients how they felt about taking medication, and how they could make it easier by placing the pills next to their toothbrush so that they would remember to take the pills every morning and evening. Some doctors suggested switching to a combination pill that would reduce the total number of pills that a patient needed to take. Doctors treated complications by helping their patients live with the disabilities diabetes may cause. In one case a doctor helped his patient apply for reimbursement of assistive technologies in his home, and a nurse gave a patient with neuropathy a drawing of the contour of his foot to bring to the shoe shop to ensure that his shoes fit properly, since he would not be able to tell. Some doctors engaged in detailed weight-loss planning of or smoking cessation by setting short-term subsidiary goals.

I learned much from the time I spent in the clinics, but most important for my analysis was the interactions between doctors and patients. I made my observations with a video camera by my side. It was not running all day, but used for recording the clinical encounters relating to diabetes or hearing loss. With the recordings, I was able to return to the documented interactions and thus

The chair I was sitting in during consultations in a clinic in New York. Next to me was the camera on a small tripod.

the relations and procedures through which the conditions were known and handled. As Suchman and colleagues observe, recordings capture the details of just how skillfully and dynamically meaning-making work is put together. Unlike an interview, video captures what is least likely to be mentioned by participants; because it is so fundamental to practice that it is unremarkable to them (Suchman et al. 1999:398). Making the recordings turned out to be less problematic than I had expected, even though I did not spend the same amount of time getting familiar with the doctors as I had in my master's research. In some cases the patient had been notified a few days in advance by the doctor, but in other cases they were asked permission as they arrived in the clinic. I would always explain to them what I was studying and how I was going to use the recordings, before asking them to read and sign a consent form. As soon as I had introduced myself, I would withdraw from the interaction, often sitting quietly in a corner of the room with my notebook, trying not to interfere with the clinical encounter. Even though the formalities drew attention to my presence, I was surprised to see how soon people seemed to forget it, and engage in the clinical encounter. I ascribe this to the general acceptance of studies in medical practice. Several patients I met had been involved in medical studies and were accustomed to the presence of assistants in the clinical room, and it did not appear problematic to be a researcher in the clinical context.

Interviews

In the clinical encounter, I was interested in documenting the ways in which patients and doctors interactionally made sense of and reacted to hearing loss and diabetes. Maintaining this approach as I was shifting locations from the clinics to the homes, posed an immediate challenge. When I met people in their homes, the conditions were rarely observable to me. The hearing-impaired did quite well in a face-to-face conversation with one other person, and the people with diabetes showed no symptoms of their elevated blood sugars. In other words, there were no enactments of the conditions playing out in my presence. The approach I took was seeing people as ethnographers in their own right and attending to their observations and interpretations of their lives with the conditions. Mol suggests that by listening to our informants as their own ethnographers we may gain an understanding, not only of how it feels to live with a physical impairment, but how 'living with an impaired body is *done* in practice' (2002:15, author's emphasis). With this approach, the situated enactment of diseases is still foregrounded, even if the methodological approach shifts from participatory observation to interviewing people about their disease. Through my conversations with people I learned how their condition emerged in problematic situations and how they dealt with these. There were though more to the stories that people told me than mere descriptions of practicalities and events, as Mol suggests. The conversations I had with people in their homes also taught me how they selectively assembled and interpreted events in a meaningful account. With ethnomethodological sensitivity to the context and construction of the descriptive representations informants produce, I attend to the interviews not only as reports on events, but also as situated sense-making (Pollner and Emerson 2001:126). I therefore study not only the practice of doing a disease, as Mol suggests, but also the practice of meaningfully constituting what people take to be real (Gubrium and Holstein 1997; Pollner and Emerson 2001).

We visited a total of 21 people in their homes (see page 50), most of them twice, but some only once. I would always start the interview by introducing our research project and say that we were interested in their experience of living with their condition. For some people this was enough to get them talking, and the conversation would go on from there. When that was not the case, I would ask questions like how long they had had the condition, how they first noticed it, how they had handled it and how it affected their everyday life. In our conversations, people shared their stories about living with the conditions, soon embedded in stories about their other concerns, their personal history and relations to people who were close to them.

My interview material is a mixture of shorter talks in the clinic and longer conversations in the homes. As I pointed out in the discussion on ethnomethodology, stories elicited through interviews are situated accounts, produced in relation to the interviewer and situated in time as well as in a particular context. In other words, the patient does not carry around a single perspective or understanding, as sometimes seems to be the suggestion, when the notion of 'illness narrative' is used to denote the patient's experience (Steffen 1997:99). The stories being told are inseparable from their situated performance. Displacing myself between different sites made it obvious that the accounts I came across had been composed in situ, relating to an understanding of the situation and to me. In my short follow-up interviews in the clinics, I was situated within the clinical context. One diabetes patient thus oriented to me as part of the medical staff, and when we sat down to do the interview asked me 'is it true that people can lose their legs because of that kind of extreme condition?' Another patient I met in a clinic related to me as a researcher, who was doing some kind of evaluation of the clinical work, and repeatedly pointed out that his doctor was doing a great job: 'you do not find a better person to control this, he is very attentive and in my opinion very good at controlling my diabetes, and cares a lot that his patients are as good as possible'. In the clinics, I consistently introduced myself as a researcher from the social sciences with no medical training and no interest in judging the clinical work, but eager to understand their experiences and stories. However, my intent of setting the scene for the interviews competed with the actual site in which we found ourselves.

When I visited people in their homes, they related to me differently. Here I was often assumed to be an ally in their stories. Mona had had diabetes for more than a decade. She confided to me that she had felt neglected by her doctor and did not trust him. She said she had the impression that he did not care about her and tried to solve her problems by prescribing pills rather than listening to her. When I interviewed people with hearing impairment with their spouses, I often found that I was oriented to as an outsider to whom each spouse provided one side of the story.

The stories did not only relate to me, but were also situated in a context and specific understanding of the past and expectations for the futures. In this regard, there is one interview with a hearing impaired man that stands out to me. As we were talking about his hearing problems, it soon emerged that he was determined to obtain hearing aids. When I asked how he had noticed his hearing difficulties and how he decided what to do, he told me without any doubts that he did not hear well and needed to do something about it. The interview did not really flow, and I tried to ask about the details, possible doubts and other people's reactions, but his account was unambiguous; he told me that he simply did not hear well anymore and that his hearing loss was noticeable both to him and to people around him. In the moment, I felt like a poor interviewer unable to ask the right questions. Later I came to understand his account as a retrospective analysis informed by his understanding of the presence; that he no longer heard well enough.

The most interesting interviews about hearing loss, which tended to last for hours, were with people who were still trying to find out about their hearing difficulties, and who talked about their experience as situations of doubts, trying out different solutions and moving among alternate interpretations. The people I met with diabetes had been diagnosed and did not have the same uncertainty about their condition. Even so, I met a similar kind of variation in my interview material. Some talked about their condition as something that had been taken care of; it was regulated with medication and there was no reason to be concerned about it. For others, being well regulated was in itself a source of concern, and might cause fear of forgetting the silent but potentially dangerous disease. Yet others would talk about events that had changed their relation to diabetes from a non-symptomatic risk to a disease with painful impact on their body.

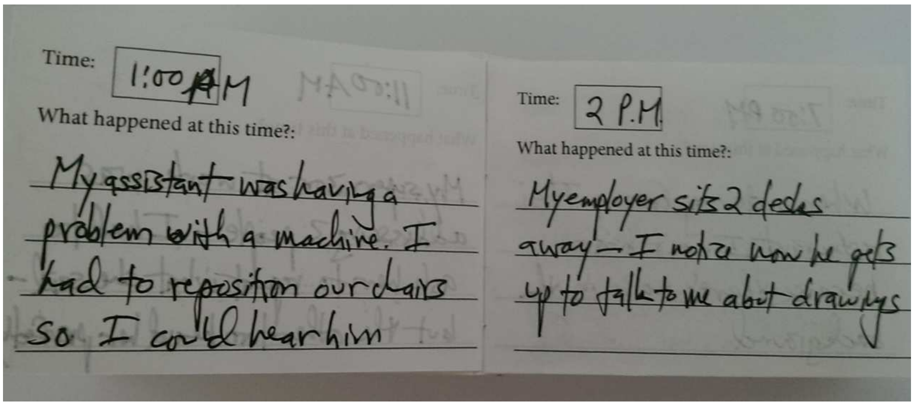
My consequent attending to the practicalities of dealing with hearing loss and diabetes, means that I am interested in describing the details of situated practices, and not in life stories. This thesis is therefore inhabited with active, interacting people handling situations as they appear problematic to them. We do not get to know them as characters in an unfolding and lengthy story about their lives, but just well enough to understand their part in the situated interactions.

Auto-ethnography

Recognizing that the events people told us about in the interviews are retrospectively assembled in situ, we supplemented the interview with tools that encouraged people to make observations in their everyday lives and write down these events on the day they occurred. The hope was to get richer empirical material that took us closer to the everyday events by making people notice the details in concrete situations, some of which might have gone unnoticed, had it not been for the observation tools. Our first intervention of this kind was a diary we handed out to five informants in 2009. At that point we asked people to describe situations that related to their condition, explain what happened and what they thought and felt at the time. The task was very open-ended and did not probe for problematic situations, but simply asked people to observe the impact of their condition in everyday life. Towards the end of our fieldwork this idea of a diary was developed along with our interest in practices of measuring and assessing health conditions. The auto-ethnographic tool kit that we designed encouraged our participants to make systematic observations about their conditions. The tool kit for hearing loss consisted of a credit card-sized

The hearing loss auto-ethnography kit contains a notebook and a camera with instructions for the two tasks.

notebook, titled 'Mapping Hearing Problems in Everyday Life' and a small video camera with instructions for two tasks: to record situations in which hearing problems occurred and to have the participants interview someone close to them about their hearing impairment (see picture). The participants had one week to complete the tasks, and then we came back for a second interview where we talked about their observations. The notebook for mapping hearing problems was thought to generate an alternate assessment of hearing impairment. It consisted of a grid to register the occurrence and time of a hearing problem, and supplementary pages for descriptions of the situations. The idea was that people chose one day and wrote down the problems that had arisen on that day. The notebooks for mapping problems provided us with a rich and detailed material about specific situations and how they were handled. In the follow-up interviews, people would often talk about their condition in much more detail than in our first meeting, and some were quite surprised to see how many times they had registered their hearing to cause problems. The tool kit helped articulate other stories about the everyday lives with the conditions and brought us closer to the moment-to-moment practices of dealing with the health condition.



Time: 1:00 PM

What happened at this time?:

My assistant was having a problem with a machine. I had to reposition our chairs so I could hear him

Time: 2 P.M

What happened at this time?:

My employer sits 2 desks away – I notice how he gets up to talk to me about drawings

One participant recorded a noisy machine at work, and described how he handled a hearing problem in its presence.

An exhibition

As a closing event of our research project, we arranged an exhibition for the employees in Oticon and Novo Nordisk. We presented extracts from our ethnographic material, analytical thoughts and design concepts under the title: ‘Do we create problems and solutions?’ The aim was to articulate the assumptions that underlie the design of hearing aids and insulin pens and provoke discussions about the relation between the problems of the chronic medical conditions and the treatment devices. With stories from our fieldwork we sought to indicate that the anticipation of the treatment devices brings forward only some aspects of the medical conditions. With a number of critical design concepts we suggested different ways of intervening and addressing other versions of the medical conditions[10].

Most of the thoughts behind the exhibition were those that Janet and I had shared and refined over the course of our research project. In the practical composing of the exhibition, I was responsible for choosing extracts of interaction and formulating the texts in the ethnographic part of the exhibition. The design ideas had also developed over the course of the project; some of them reflected ideas we had discussed early on, while others were developed specifically for the exhibition and were to a larger extent Janet's sole contribution. Janet designed the concepts in the exhibition, while SPIRE undergraduates created the drawings and built the stands.[11]

This design anthropological achievement was a shared critical articulation of the taken-for-granted understandings of users, medical conditions and treatment devices at play in the companies and reflected 'a collaborative effort between designers and anthropologists studying, conceptualizing, and experimenting with potential relations between people, practices, and things' (Kjærsgaard and Otto 2013:188). At the same time, the employees' responses to the exhibition made the empirical grounds for further inquiry. The conversations that took place during our guided tours and on a written feedback stand, revealed a myriad of assumptions, logics and concerns about users and devices.

THE ANALYTICAL WORK

Ethnographic curiosity and situated analysis

My ethnographic path evolved from what was 'given' in the project, my own discoveries, and also through close collaborations and interaction on the way. Methodological reflections on the crafting of anthropological knowledge often bear witness to the importance of choices made on the way (Sanjek 1990, Strathern 2011). The fieldwork is associated with the ethnographer's personal curiosity and wonder (Hastrup 2003b) and the analysis described as a dialectic movement between mind and matter, between the ethnographer's ideas and the ethnographic material (Sjørslev 1995). In the case of my cross-disciplinary and industrially embedded project, the analytical figure that emerged on a motley ground of empirical material is not best described

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[10] I will describe the composition of the exhibition in further detail in chapter six. In describing how we arranged the ethnographic material and design concepts, I also discuss how we communicated our message to the companies, which is important for understanding how employees responded. Therefore the discussion is located in chapter six, and not here, even though it also includes considerations of methods.

[11] We are particularly grateful to Thijs Roumen for building the exhibition and Agnese Caglio for making the scenario drawings.

as the result of my curiosity and decisions alone. The contours of the analytical figure in my work, largely took its form from the relations to other people involved in the project. As I have explained above, my involvement with the two companies set the frame for the empirical object of study. Their 'barriers to treatment' stance also shaped the analytical attention, if not in a search for barriers, then in a curiosity about alternate relations between people, diseases and treatments. It was largely because of my relation with design that themes emerged early in the project – with consequences for the proceeding fieldwork and my analytical attention. My pragmatic starting point and the ethnomethodological attention to details in interaction steered my curiosity towards the dynamic and skilful productions of the conditions. From this interest in particular enactments of relations between conditions and their treatments, I noticed that doctors and patients often oriented to the conditions by way of medical evidence: the audiogram and the blood sugar numbers. This early empirical observation became a shared interest steering both the ethnographic fieldwork and design interventions that aimed at alternate ways of measuring and assessing. (We shall see some examples in chapter six, see also Kelly 2014.)

Writing up

When I started preparing for the writing of my thesis, I decided to pay careful attention to people's orientations to measurements and alternate assessments. I transcribed the majority of my material in NVivo[12], a qualitative data analysis software program, and with help from a MA-student, smaller extracts were transcribed in CLAN, a software for transcription used in the field of conversation analysis[13]. I usually started with rough transcripts and from these, I selected sites of special interest for more detailed transcriptions. The pieces I selected were informed by the themes, Janet and I identified early on, most importantly on *measuring*, but also including the tension between wanting to live a *normal life* while being a *patient*, and how people dealt with this problem. The comparison between hearing loss and diabetes also directed attention to the social and physical aspects of the conditions. At first it appeared that hearing loss was a social impediment, while diabetes was an individual and physical condition. This observation, however, led us to explore how hearing loss also figures as a physical and individual, sensory impairment, while diabetes too is associated with a strong and socially mediated moral aspect. As the transcriptions took form, I started coding my material in NVivo by use of 'nodes' informed by these themes and ideas, but also hoping to find more. I did not code all the material, but only the most interesting sections and then read over other parts, searching for material that related to these

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[12] There were a few interviews, which I early decided not to study in detail – amongst others the interview with the man who had decided to get hearing aids, and where I felt I did not learn much from the interview.

[13] This was early in the project, before I gave up integrating my anthropological work with conversation analysis in favor of an ethnomethodologically informed approach to my ethnographic work.

codes. As I thus assembled pieces of empirical material, my analytical themes became more solidly grounded in ethnographic observations. On the theme on measuring, I came to the understanding that medical evidence did not stand alone. The hearing test was made sense of as it was related to the patient's experience of hearing, and the blood sugar test was understood in relation to preceding food intake and exercise. This assembling of evidence, sensory experiences and past events transformed the condition to a medically solvable problem. My attention to the practical assembling of problems and ways in which they were handled was inspired by earlier work with pragmatic analysis of medical practice as well as the ethnomethodological literature with which I was becoming acquainted. However, it was also enforced by Janet sharing my enthusiasm for this conceptualization. From a design perspective, she was curious not only about how people handled their disease problems, but also in ways to intervene in and craft a solvable problem for design (Kelly 2014). Inspired by anthropological literature on the enmeshment of available solutions and the emergence of problems (Jöhncke et al. 2004, Keller 1992), I realised that available medical treatments did not only figure as solutions, but also shaped the selective process of figuring the problems. When we were putting our exhibition together, we conceptualized the diseases inspired by the vocabulary of Dilley, as an emerging figure resulting from selective connections made between bodies, devices, sensations and past experiences, while other features faded into the background (1999). Later on, as I was writing up my thesis, tying together the different theoretical positions, I developed this conceptualization with the notion of 'configuration' that I came across in the work of Suchman, whose work provided not only a very useful analytical tool, but also an inspiring bridging of ethnomethodology, anthropology and design (Suchman 2000, 2007, 2011).

Design and analysis

Writing a thesis is an activity that shapes the analysis into the particular format; a text structured in chapters, though hopefully continuously unfolding. Beyond this written document, the analytical work took on other forms during the project. In the design activities, we produced various materialized representations of our understandings of the field, which made for other analytical formats and ways of presenting ethnographic material.

Where anthropology is most often interested in understanding the world that people presently inhabit, design is oriented towards other possible futures. In our design activities, ethnographic material was taken from a stance of possible interventions. In the workshops, we worked mainly with critical artifacts, designed to embody controversies and provoke reactions by disrupting social norms (see Kelly 2014). They were tools that turned present practices on their head. On the theme on measuring for example, we composed artifacts that did not measure the blood sugar values of the body, but measured food intake. For instance, we made a concept with a plate that indicated how healthy the food on it was. The concept provoked discussions about privacy; people did not want to reveal to others if their food was healthy, and one participant even said she would cheat to make her food appear healthier. It also opened a discussion about the problem of transforming a dinner into its nutritional value. Apart from articulating social norms in a way that I had not experienced during fieldwork, the work with artifacts drew my attention to technologies and their impact on people's understandings of and life with a medical condition.

In the exhibition ethnographic material was assembled to bring across the message that medical conditions are locally produced and configured *with* technologies, and hence might be figured differently if technologies were altered. In this context, the analytical work was shaped by a format quite different from the writing of my thesis; it had to be brief and raise curiosity in order to make employees stop up and take a closer look. With the exhibition my analysis took form of a critical articulation of the companies' current understanding of the relations between the 'pre-users' suffering from a medical condition, and available treatment technologies, inviting them to see things from a different perspective.

I see the analytical current in my project as composed of numerous tributaries converging in an unforeseeable movement, and not only as the result of my curiosity. In her claim for a 'binary license' Strathern highlights the moment when the anthropologist chooses among terms and takes analysis down one road and not another (2011:90). I undoubtedly found myself at such cross roads, but I believe that the process that brought me to the bifurcating roads is as important as my choosing one road or the other. In the spirit of my theoretical stance, I see my analytical work, not as the result of my thoughts and choices, but of a situated and constantly adjusting movement.

CONCLUSION

At the beginning of this chapter, I sat out to render visible (some of) the work in and through which my field is accomplished. I follow Dewey's understanding of 'data', not as what classical empiricists denoted to be 'given' to us as observable, but rather what is 'taken', which allows for a more radical notion of our experience of the world as an engaged, interacting and interested way of being in the world (Boisvert 1997; Dewey 1929). Knowledge production is not a matter of collecting the observable, but of actively and selectively foregrounding certain aspects of the world, while leaving the rest in the background. However, as Donna Haraway has demonstrated, much science is written as if it had been everywhere, which enables it to appear to talk from nowhere at all. The perspective of knowledge-making practices, she argues, is always partial, not simply because it is selective, but importantly, because it is embodied, situated and located. By drawing attention to the positions from which knowledge does not usually emerge, the subjugated position, she renders visible the situated character of knowledge (Harraway 1988, 1997). This chapter has rendered visible the positions from which I worked, and the methods through which my ethnographic material was brought about.

In the rest of the thesis, follows an account about what I experienced in the field. It is composed by assembling pieces of ethnographic material generated from these positions I had and through the methods I have discussed. While, I hope it appears as a coherent analysis, I also hope to have demonstrated how it is the result of a situated and engaged movement of interacting with people I met in the field and people I worked with, and selectively following an ethnographic curiosity.

CHAPTER THREE

MEASUREMENTS

This chapter takes the first step in turning the matter of treatability into an empirical question. Rather than assuming the problems of diabetes and hearing loss to be ‘given’ measurable entities, I explore what makes up the problem of the two medical conditions for the people who live with and handle them. This movement involves a redirection from a search for ‘barriers to treatment’ understood as reasons why people do not adhere to treatment recommendation and follow a medical rationality, to a focus on how they actually engage with and inquire about their medical conditions.

As we started our fieldwork in the clinics, one of my first observations was that patients and doctors frequently oriented to the medical conditions by way of numbers and other medical evidence. The diabetes review consultation centered on the test results from the lab, the patient’s home measuring, short-term blood sugar measured in the clinic or the weight recorded on a scale. The hearing consultation centered on the hearing test. The occurrence and production of medical evidence in a clinical encounter is not surprising. On the contrary, argues Good in his introduction to ‘Medicine, Rationality and Experience’, making a diagnosis by use of physical examination and tests is a primary task of clinical medicine (1994). Good identifies an ‘empiricist theory of medical knowledge’, according to which diseases are given as universal entities, that may be measured by clinical procedures, which allows for intervention in the disease mechanism (ibid:8). He suggests that this understanding makes for a folk epistemology, since it is shared by members of society and is foundational of clinical practice. According to this understanding, contemporary medicine provides objective knowledge represented as a transparent reflection of nature. This objective *knowledge* is contrasted with the patient's personal *beliefs* or psychological condition and allows medicine to assuage the patient's uncertainty by revealing a scientific *truth*. This understanding of medical practices resonates with the assumption in the 'barriers to treatment' stance, outlined in the previous chapter, in which the patient suffers from a medical condition that can be *known* objectively, though certain *beliefs* may inhibit the patient from starting treatment. In this sense a medical condition is treatable when it is responsive to treatment and the questions about barriers therefore centre on beliefs rather than knowledge.

In the light of this empiricist theory of medical knowledge, Good sees it as the task of medical anthropology to bring attention to human experience, meaning and interpretation. This chapter attends to the meaning-making and interpreting work done in clinical interactions. My point of departure is to see medical knowledge production as a skillful practice conducted by specific people as they use certain equipment and procedures in a social and material setting. This does not entail denying the existence of an objective biomedical disease, but turning attention to the practical procedures for creating and sustaining what those doctors and patients treat as real. In other words, I work from the primacy of interaction, as I described in chapter one. I take the body and its health conditions as emerging through the embodied work in the clinic. I follow Dewey's advice and start with things in their complex entanglements, leaving behind commonly accepted distinctions like knowledge and belief, object and subject, the pathologic and the normal to examine them as products of embodied, located meaning-making work. From this stance, I study doctors' and patients' techniques for selecting, discriminating and relating observations to form an object of knowledge (Dewey 1929:143). I explore the ways in which the body and its medical condition emerge with and through the practices for knowing (Mol 2002:5, Dewey 1929:157).

As I observed above, measurements and the associated production of materialized representations play a central role in my ethnographic material. However, doctors and patients did not simply orient to the medical evidence as answers and scientific truths, but also a source of new questions and further inquiries into the patient's experience of past activities and sensations. By relating the numbers to certain events, observations and actions in the past or possibilities in the future, the medical evidence became meaningful.

I will develop my analytical stance by use of Goodwin's 'professional vision', generated through a detailed empirical analysis of how objects of knowledge are produced in a professional setting (1994). Despite its apparent focus on 'seeing', Goodwin's interest in vision is not limited to a narrow perceptual event, but understood as an active embodied practice (Suchman 2009:4).

He is concerned with the procedures in and through which an object of knowledge emerges, and he develops a vocabulary for the practices that participants apply to build and contest professional vision. He includes the following practices: the production of *material representations*, in my case the audiogram or the number on the display of the blood glucose meter; *coding*, in which the world is transformed into categories relevant to the profession; and *highlighting*, which marks a figure on a ground, so that phenomena relevant to the activity stand out (Goodwin 1994:608-11). With this terminology, I will unfold how doctors and patients use measuring technologies in their meaningful productions of hearing loss and diabetes.

The chapter starts with an examination of how doctors and patients collaboratively produce material representations through embodied practices of measuring. In the following section I move on to show how doctors and patients collaboratively make sense of the test results. With the concepts of highlighting and coding, I first explore how doctors and patients categorize and transform features of the body's condition and functionality into numbers and diagrams. I then show that patients' everyday experience is selectively transformed to enter a meaningful relation with the test result. I argue that neither medical evidence nor patient experience make sense independently of each other. What we might commonly distinguish as *objective knowledge* about the body and *subjective experience* of and beliefs about it, emerge in relation to each other. I show that subjectivity, like objectivity, is contingent and locally produced.

MEASUREMENTS AS EMBODIED PRACTICE

In this section, I examine the way in which measurements are made as an embodied practice. As I observed above, we assume that medical practice involves physical examination, tests and medical evidence. In this section, I suspend this common preconception to 'make the familiar strange'. Through a detailed analysis of interactions among doctors, patients and medical measuring technologies, I show how material representations of selected features of the body are transformed to a number on a display or a curve on the audiogram. What we usually take as objective knowledge or scientific truth about the medical conditions, is collaboratively produced. I am going to focus on just one kind of measuring in each condition area: the blood sugar measurement and the pure tone audiometry[1].

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[1] The examination of the patient often involved other tests. For diabetes, cholesterol, blood pressure and weighing were among the tests that were most frequently used. For hearing, a physical examination was always done to exclude conductive hearing loss, as well as an examination of nose and throat. The reason for focusing on the blood sugar test and audiometry is that these tests usually are central to the evaluation of need for treatment with insulin and hearing aids.

Blood sugar measurement

In a general practice clinic in Copenhagen, Henrik, who had had diabetes for a year, came in for a review visit with Martin, his physician. Martin asked if Henrik was following his treatment regimen, and Henrik replied that he found it hard to do exactly as he was supposed to. Martin then suggested measuring Henrik's blood sugar. In this case the examination consisted of two tests: a long and a short-term. The long-term (HbA1c) is usually done at the hospital or a lab. However, this clinic was equipped with machinery for testing the long-term sugar, which martin called 'the snitch' because of its ability to reveal the average blood sugar over the past three months. In the following extract from the consultation, the blood sugar level was measured:

Martin fetches a little box and some needles that he places on the table. He reaches out to Henrik, who leans forwards and places his hand on the table, palm up and the forearm resting on the edge of the table.

Martin: Now we will see from the snitch here, how it is…

Martin pricks Henrik's finger. He then puts down the needle and presses out a drop of blood, while Henrik quietly looks at the finger.

Martin: Have you been very tired? Or, do you think it has been the same?

Martin places a strip on Henrik's fingertip to absorb the blood.

Henrik: I think that I am often tired. I get tired quickly.

Martin takes the strip away from the finger and inserts it into the plastic box on the table.

Martin: Well, that was the long-term, and…

Martin picks up another strip and repeats the procedure. He inserts the second strip into the blood glucose meter, and waits for the number to show. He frowns and then reads out loud:

Martin: 11.3, that was kind of high.

Henrik gives him a serious look, licks his finger and leans back into his previous positions, leaning back and arms folded. Martin picks up the plastic box with the sample for the long-term test from the table and gets up.

Martin Well, we'll see it from…

Henrik: I will do better.

Martin: Well, it is a little difficult now, Henrik. It seems like you should have some more medicine. But, if it is because you have not taken the medication, I think you are taking - then it is a different matter, right?

Henrik: I must try to do better.

In this short interaction, the blood was selected as the relevant site to collect data about the state of the body. 'The snitch' would tell the truth about Henrik's compliance with treatment. In Dewey's terminology, it was selected for the purpose of serving as evidence. The blood sample

Martin (right) measures Henrik's blood sugar.

was inserted in the glucose meter and transformed to a number on a display, and *became* data for the evaluation of the diabetes (Dewey 1929:143). This practice of measuring was but one source of knowledge produced in the clinical encounter. The dialogue during the test indicates that how the patient felt and what he had (not) done were other features of the meaningful production of diabetes. I will now examine the relationships among diverse features in the consultation. Before doing so, however, I will turn to the practice of measuring in hearing care.

Pure tone audiometry

In an ear, nose and throat clinic just outside of Copenhagen, Svend would like to have his ears checked. The doctor, Sebastian, asked what brought him in, and Svend explained that he suffered from a clogged sensation and suspected that some ear wax was blocking his ear canal. Sebastian performed a physical examination and concluded that Svend's ears looked perfectly fine. He excluded conductive hearing loss and decided that a hearing test was needed. His assistant, Ursula, conducted the hearing test. She asked Svend to sit in a chair by the audiometer and then instructed him about the test as she set it up:

Ursula: You get this one to press on (*she hands him a device with a button to press*), and then you must have these on. (*She brings him a pair of headphones)*. Then, I will take your glasses. (*She removes them and puts them on the table)*.

Svend: Yes, that is okay then. Is there something about me hearing some sounds and doing something?

During pure tone audiometry, the assistant (left) faces the dashboard, while the patient (right) is fitted with headphones, presses a button, and looks into the distance.

Ursula: Yes, whenever you hear something, you press that one. (*She points to the device in his hand*).

Svend: Yes, okay.

Ursula fits the headphones over his ears.

Svend*:* Will it come in one ear or both of them?

Ursula: One at a time.

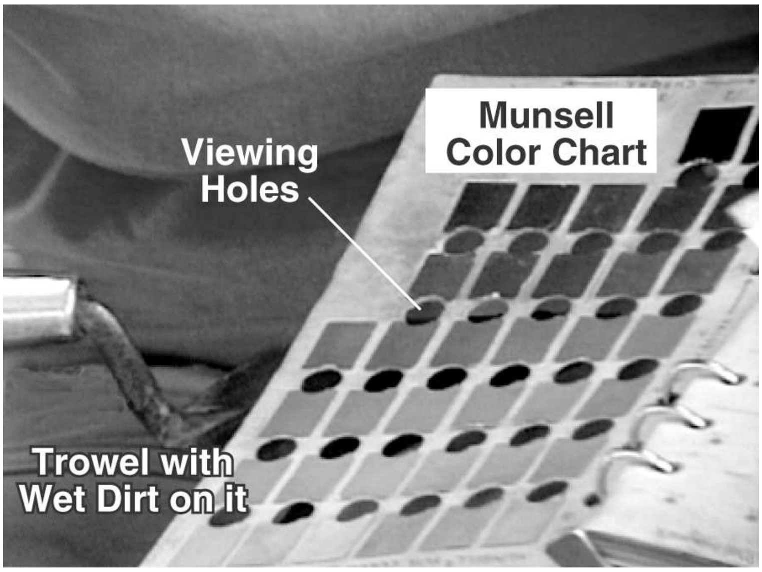
When the headphones are set, Ursula goes to her audiometer and looks down at the dashboard. While she operates the audiometer, Svend sits with the device in his hand and presses the button every time he hears a tone.

The embodied work of producing the audiogram differs from the blood test. It is not skillfully conducted in silence. On the contrary, Ursula carefully explained to Svend how to take the test, and Svend followed her instructions. During the test they did not look at each other and they remained silent. Each was oriented to the work of conducting the test, and producing the medical evidence, and both of them treated the relation between Svend’s ability to perceive and react to the sounds in the headphones as an object of knowledge. No blood or tissue samples are extracted, and the object of knowledge emerges from their collaborative effort mediated by the instrument; Svend signaled when he heard a tone, and then Ursula marked the audiogram with a cross for the right ear and a circle for the left. The test result emerged as a curve on the computer screen, and later served as evidence for the doctor when he returned to the room to evaluate Svend's hearing. Before I turn to the meaning-making readings of numbers and diagrams, I will take a closer look at the situated enacting of the body as an object of medical knowledge by using the analytical tools 'professional vision' and 'body work'.

Professional vision

In the article 'Professional Vision', Charles Goodwin argues that the ability to see a meaningful event is a socially situated accomplishment; it is something learned by practitioners of a profession through the interplay of practices with their associated materials and tools (Goodwin 1994:606). He uses archaeological field excavation as a case study, and observes that the archeologists learn to see things in a patch of soil that a farmer would not (ibid:606). Seeing involves much more than viewing, which Goodwin demonstrates with a detailed description of the practices involved in color coding a sample from the field excavation. The archeologist selects a patch of soil, moistens it and places it underneath a color chart with a hole for each colored square, to determine which color best matches the sample. At this moment, the soil is transformed according to codes that are relevant to archeologists (ibid:608). The archeologist comes to view the world from the perspective of the chart; the tool co-constitutes their professional vision. Consequently, human cognition is not located solely in the mind, Goodwin argues, but is distributed with the tools and forms for coding and transforming phenomena in the world. Professional vision also entails a definition of what is taken to be the unit of analysis; by highlighting a certain patch of soil as relevant for the activity, a figure is made to stand out against the ground of other possible material. Through practices of selectively taking and transforming the sample to a code, the archaeologist shapes the material provided by the earth into an object of knowledge (ibid:611).

Where Dewey makes the philosophical observation that data is 'taken', Goodwin demonstrates through a detailed empirical analysis how data are rendered visible through embodied work. Despite the notion of 'vision', the professional practitioner does not resemble the spectator in Dewey's work, but rather the active and embodied inquirer who examines a particular subject guided by a specific objective. 'Professional vision' provides a vocabulary for analyzing how interactions among professional medical practices, patients and technical instruments produce hearing loss and diabetes. In the case of diabetes, an object of knowledge emerges as Martin skillfully uses tools such as the needle and the strip to extract blood from Henrik's body and transforms it by use of the blood glucose meter to a material representation: a number on a display. He assesses the number that may fall into the categories of high, low or normal, which



Coding is an embodied practice. In the professional field of archaeology, it includes preparation of the soil and skilful matching of soil and color codes (Goodwin 1994, reproduced with permission).

are well known in his profession and described in its guidelines. In Goodwin's terminology, Henrik's diabetes is evaluated on the basis of what is shown on the blood glucose meter; it is figured as a number on a scale. In the case of audiometry, an object of knowledge emerges through the production of the hearing test, in which the sensory capacity to hear is transformed to discrete sounds that Svend can hear at certain decibels. Svend's response is sent by wires to Ursula's computer, where she converts them to marks on the diagram and finally draw Svend's hearing curve. In both cases, the measuring technologies bring definitiveness to the result.

Collaborative 'body work'

As opposed to the archeologist transforming the patch of soil, clinic work is not done by the professional practitioners alone, but also by the patients. With the term 'body work', Heath argues that the body as an object for medical practice is constructed during the consultation and that 'the patient in and through interaction with the doctor transforms himself or herself from an active subject to an object of inspection and investigation' (2006:187). By looking down and away, the patient allows the doctor to perform a physical examination (ibid.). In this collaborative work, the patient's body emerges as an object for medicine. In the diabetes consultation described above, Henrik allowed Martin to prick him without complaining, though the fingertip is a very sensitive site. He distanced himself from his body and transformed it into an object by withholding a response to the painful procedure. The hearing test involved no pain, no invasion of the body, but rather concentration, and relied on Svend's perception of sound, which the computer mediated and translated into a curve. By different means, both patients made their body a 'suitable site for clinical examination' (ibid:193). They were both attentive and responsive to their clinicians' expectations; Henrik by responding to the familiar device out on the table, and Svend by following Ursula's instructions. They both actively constituted themselves as clinical objects, and allow certain physical functions to be rendered clinically visible.

In both cases, material representations emerge as interactional accomplishments. The measuring technologies steer what is 'taken' and transformed into data that is of concern in diabetes and hearing care. In contrast to the medical model, where disease entities are revealed, the medical evidence about hearing loss and diabetes is shown to be carefully produced.

MAKING SENSE OF MEASUREMENTS

As I observed earlier, we commonly take medicine to be a practice that can provide truthful answers to patients' questions and resolve their uncertainty by use of examinations and tests (Good 1994). The knowledge thus produced may contradict the patients' beliefs. Empirical studies of doctor-patient interactions confirms these preconceptions, and Heath demonstrates that findings generated through examination often are treated as 'facts of the matter' in the clinical encounter, and may stand in marked contrast to the account presented by the patient (Heath 2006). In detailed analysis of clinical interactions, Peräkylä observes that deliveries of test results are often immediately followed by a professional assessment or diagnosis (2006:222). In other words, the production of diagnosis is oriented to the responsibility of the doctor, whereas the treatment decision is a shared responsibility (Stivers 2002).

Svend's physical examination, which took place just prior to the measuring is an example of this. Svend believed that he had ear wax blocking his ear canal. Sebastian examined his ears by inserting a funnel into the canal and lighting it. He immediately concluded that the ears looked fine and that wax was not blocking the ear canals. The examination of the ears was treated as evidence for this assessment. Only Sebastian had seen the ear and thus claimed authority to the evidence, as suggested in the studies cited above. The result stood in contrast to Svend's suggested diagnosis, but was also by Svend oriented to as an answer to his concern, and the medical evidence thus refuted the patient's beliefs. The simplicity of this sequence of interaction stood in marked contrast to the complexity of making sense of the evidence from the hearing test and the blood sugar measurement. While medical evidence may figure as an end point as it allows the doctor to set a diagnosis, it was more often taken as starting point for a dialogue through which doctors and patients made sense of the numbers and diagrams, to produce an evaluation of the medical conditions. In the following, I will explore how making sense of medical evidence in the clinical encounter involves assembling and modifying different sources of knowledge.

In the diabetes review the diagnosis was already known, and the encounter was a matter of continuously evaluating the status of the medical condition and making treatment adjustments. In hearing care the diagnosis and treatment choice often merge since the diagnosis is a matter of finding out if the patient needs hearing aids. Numbers do not merely represent truths, and do not act on their own, but are embedded in relations. As Dewey observes, ‘knowledge of facts does not entail conformity and acquiescence. The contrary is the case. Perception of things as they are, is but a stage in the process of making them different. They have already begun to be different in being known, for by that fact they enter into a different context, a context of foresight and judgment of better and worse’ (Dewey 1957:274). To understand the process of ‘making things different’ in the clinical encounter, I need to look at the consultation more broadly. Reading the test result takes place not only at the moment doctor and patient look at the curve or the number; it also relates to the conversations that go on before and make a particular reading possible, as doctor and patient identify possible explanations for the blood sugar level or the hearing curve. It also relates to possible future interventions. I will therefore look more closely at what happens in the two consultations.

Reading the blood sugar test

Prior to the blood sample being taken, Martin started the consultation with Henrik by asking him how he was managing to treat his diabetes at home[2]:

Martin: Do you take your pills?
Henrik Yes.
Martin: You do so?
Henrik: I try to remember, well I do forget it…
Martin: Do you get them most days?
Henrik: I get at least two a day.
Martin: Okay. Good, so you get some every day.
Henrik: It is better on the weekend, when I am at home with the wife.
Martin makes a comment about the blood sugar they will soon measure.
Martin: What about the weight, Henrik? Can we get in here and check it?

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[2] This may appear as a rather abrupt start for a consultation. The reason is that, since I was there we all greeted each other and talked about my presence as a researcher first. So the start is the point at which I sit down, and Martin and Henrik engage in their conversation.

Henrik: 109

Martin: I do not think so. Hopefully it is not that much.

Henrik: I had just lost 10 kilos.

Martin: Yes. How can it be that they have popped back on again?

Henrik: That is because ehh…

Martin now reads from the scale.

Martin: Oh, 108. Is it because you are living too well?

Henrik: Eh, I do have, I must admit I cannot… I have a hard time complying with this no-sugar diet.

In this first part of the consultation, Henrik and Martin suggested two possible explanations for their reading of test result. The first was that Henrik was not taking his medication three times a day as he was supposed to; the other that he was not able to keep away from sugar, as shown by his weight gain. Martin repeatedly prepared the reading of the result, by saying that they would see from the test result how well Henrik was doing (see page 66). He thus framed the test result as an evaluation of Henrik's compliance with his medical treatment and lifestyle changes. When Martin read the short-term sugar, he observed that it was high (page 66), and Henrik heard the number as a judgment of his previous actions, to which he responded with his promise to do better. They thus related to the number, not only as evidence of the state of Henrik's diabetes, but also as an evaluation of his failed efforts to take care of it. This was not only problematic for his medical condition, but also for Martin's work, since it made it hard for him make sense of the number, as long as he did not know how much medication Henrik had been taking. The evidence was not only treated as a *truth* and an answer, but depended on relation to other features to become meaningful. Making sense of the number depended on knowing what Henrik had and had not been doing at home.

While 'data' about the body are 'taken' through practices of highlighting and coding, the same can be said about the patient's account about his habits at home. As I sat down with Henrik for a brief interview after the consultation, he told me that he was struggling to change his habits: 'It is difficult, when you are used to living a good life. The most difficult part is the sweets on the weekends. Relaxing to me is associated with – well, that can be many things – but a cake to go with my coffee, things like that. That is the hardest part'. What in the clinical encounter was taken to be a matter of not being able to keep away from sugar and thus gaining weight, was in this account described as moments of relaxation and enjoyment, of everyday habits hard to break. His experience was thus 'taken' and transformed into a professional medical discourse, in prospect of the test that would reveal his blood sugar level.

Reading the hearing test

In the hearing consultation, Svend first presented his problem of feeling clogged. The following conversation occurred while Sebastian conducted the physical examination and took Svend's history:

Sebastian: At home, what do you feel at home? Is it hard to hear the TV or anything like that?
Svend: Err… I have some difficulty hearing on the phone.
Sebastian: Yes, okay. What about when you talk with people sort of-
Svend: Err... well that does not cause me any big problems.
Sebastian: It is not so that you need to have things repeated and such?
Svend: Na, not really.
Sebastian: Not really. Okay. Good.

Sebastian explored how problematic Svend's hearing problem was, by asking about very specific situations. The questions were thus a way of categorizing Svend's hearing experience in terms of situations that Sebastian knows to be problematic. Such questions were almost always included in the hearing consultations, I observed, and in the literature it is termed a 'self-report' that the health care professional uses to understand the patient's experience (Taylor 2007). In a study of the construction of medical disposals in clinical interaction, Berg argues that physicians transform patients' problems into solvable problems, not by uncovering, but rather by '(re)-constructing' history and examination data with a treatment in mind; 'the *type* of questions a physician asks *selects* the information which corresponds with the transformation she has in mind' (1992:156-7 original emphasis). The patient's experience is 'taken', as it is filtered through predefined situations. As the conversation progressed, Svend himself brought up the point that he had not been taking good care of his ears:

Svend: But I have not been treating my ears well. I have been working in a lot of noise.
Sebastian: What have you been doing?
Svend: I am a blacksmith.
Sebastian: So it is knocking, cutting and burnishing?
Svend: Yes, burnishing.
Sebastian: And back in those days one did not use hearing protection...
Svend: No absolutely not, ha ha. So it must come forward at some point.

Here Svend offered a new explanation: he had been exposing his ears to noise. After the test was conducted, Sebastian showed Svend the audiogram and explained:

Sebastian: When we measure your hearing, it looks like this.

Sebastian turns his screen towards Svend, and looks at it. Svend gets up from his chair to stand in front of the screen.

Sebastian: The red line is your right ear and the blue line is your left ear. And the low frequencies, and actually the middle frequencies, you hear quite well. But as you can see, it then goes downwards here. *(Sebastian is pointing to the screen while explaining).*

Svend: Yes.

Sebastian: And then it makes kind of a hammock here-

Svend: On both ears?

Sebastian: A little more on your left ear than on your right ear.

Svend: Yes, yes, okay.

Sebastian: This is very typical for someone like you, with your job, that is, blacksmith and noise; it causes a loss like this.

Sebastian makes a curve with his hand to illustrate the shape of the curve.

Svend: Mm. Mm.

Sebastian: Err, and then you may say, well this also explains some of the problems you are having, well; you may call it hearing problems. The reason why you do fairly well, that is because; you hear many of the tones practically normally.

Svend: Yes.

[…]

Sebastian: What I am to tell you is this; back in the days we would not have been able to help you. But, if you feel you have problems, there have come some hearing aids that can amplify the hearing in this area, while keeping your good hearing, where you hear well.

Svend: Mm. Mm.

[…]

Sebastian: So you can go home and think about it. See how it goes…

Svend: Yes.

Sebastian: And then maybe in six months time or a year, you will say to yourself: ‘now I have more problems’, and then we will reconsider.

Svend: Yes, because it is not getting better, only worse…

Sebastian: Yes, and there is the age on top of that.

Svend: Yeah, and I do still burnish and I do not always use those things, it is really stupid (*laughs*).

Sebastian: Yes, that is not good (*laughs*).

Svend: I will have to agree (*laughs*).

Sebastian	Yes.
Svend:	But what about that area, is it so bad that you would think, err, that it would be kind of natural for me to get a hearing aid?
Sebastian:	Yes, if you came in and said, well, I do think I have big problems. That would be, talking to people and such; when there are more people, and you have big problems in that situation, then you get hearing aids.

The test result was read out and the doctor made an assessment that referred back to the explanations made available during the conversation; it was typical for a blacksmith to have the problems Svend had described. Sebastian subsequently called them 'hearing problems', as they were made to be a consequence of the measurable loss. Sebastian accepted Svend's story Svend about not using protection as an explanation for his hearing loss. However, this behavior was not made into a matter of 'lifestyle' that should be altered, but rather a part of Svend's 'life condition', a circumstance in his life, that he was not morally obliged to change. As Sebastian moved on and suggested that hearing aids could be a solution, it was conditioned by Svend's feeling of being bothered by his hearing deficit. In response to the information and the choice he was offered, Svend asked for a medical advice based on the test, but was told that it depended on his own assessment of the extent of the problems he is experiencing. Sebastian explained: 'This is how it is; if you come in, and if you personally do not think you have problems, then you will not put the hearing aids on. You need to feel you have a problem, and then – usually – you will feel like using the hearing aids'. The inquiry into Svend's hearing located a problem with a possible future solution; a hearing aid requires continuous practical work and Svend needed to be sufficiently inconvenienced to want to make the effort. This is a point upon which I will elaborate in chapter five. For now, I observe that the medical evidence was treated as a partial truth about Svend's ability to hear, whereas the other part depended on Svend's subjective assessment. Where Svend expected the medical evidence to allow his doctor to give a treatment recommendation, the doctor treated the diagram as a source of information that Svend could use to make a choice.

The partiality of measuring technologies

The measuring device affects what is measured. In the embodied practice of measuring, certain features of the body are highlighted and transformed into materialized representations. The measuring of blood sugars foregrounds certain aspects of diabetes and guides a particular conceptualization of everyday life as causes of elevations or drops of the blood sugar. The audiogram provides possible explanations and guides the mapping of everyday events as problematic or not. As Goodwin observes, professional vision is mediated by tools. An object of knowledge or the unit of analysis emerges as measuring technologies and the ability to see events of relevance for the clinical problem inform each other (1994:626). In this process certain aspects are foregrounded, while others fade in the background. This was not only observable in the clinical encounters, but also pointed out by the doctors in my conversations with them. In a break between consultations, general practitioner Mogens told me that he disagreed with the amount of attention given to blood sugar levels. In my fieldnotes from our conversation, I wrote:

> Had diabetes been discovered today, it would not have been named anything to do with sugar[3] – but rather to do with atherosclerosis since that is what causes the main complications. The main problem of diabetes is the lack of blood circulation it causes… the nerves and the small vessels are damaged. It is a shame that the patients are so focused on their blood sugar – since that is not really what matters. When I asked him what *did* matter, Mogens replied that it is the whole package; quit smoking, keeping cholesterol down, keeping blood sugars low, lose weight, eat healthily and exercise. These things are addressed in diabetes care, but with the measurements, the blood glucose level is often seen as the treatment goal.

In relation to the blood glucose measurements, diabetes is configured as a measurable 'sugar disease'. The blood sugar measurement draws attention to just *one* feature of diabetes, and makes not only doctors, but also patients see diabetes in terms of the number on the blood glucose meter. This focus of attention affects the treatment goal. Another doctor told me how she asked her patients not to show her the little notebooks in which they recorded their home measurements. She did this, she told me, so they would not become obsessed with getting the numbers right. She preferred having them keep the numbers to themselves, and talk to her more generally about how they were doing.

In hearing care, one consequence of measuring hearing is that it concentrates on the patient's ability to hear pure tones, not his or her ability to hear actual sounds and voices. . As Anna, an ear, nose and throat doctor explained to me:

> One can have good hearing and be bad at distinguishing noises. One can be terrible at using one's hearing and not be able to hear what is being said, but a hearing aid does not help in that case. When we measure people's hearing, the audiogram cannot stand alone. It only shows something about how people hear certain tones at particular frequencies in a soundproof box, not about what they hear – hearing is perceived in the brain.

The audiometer measures only part of what makes up hearing, Anna explained, while the sensation of hearing is accessible only to the patient. The audiogram was therefore always accompanied with 'self-reports' by the patient on the occurrences and extent of the hearing

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[3] In Danish, the household word for diabetes is 'sukkersyge', which literally translates to 'sugar disease'.

problem. The measuring technology did not stand alone in the figuration of hearing impairment in the clinic, and we may think of self-reports as another device for coding and transforming the patient experience. While these 'operations of inquiry' (Dewey 1929:157) produce different versions of hearing loss – one about the ability to hear under test conditions, and the other about hearing in real life – both support the understanding that hearing takes place in the brain and is ultimately the patient's personal experience.

In chapter one, I introduced Suchman's conceptualization of meaningful relations between persons and objects as a matter of configuration. In this conceptualization, the blood glucose meter and the audiometer configure particular versions of diabetes and hearing loss. With the blood glucose meter, diabetes is figured as a disease manifested as high blood sugars, which are again related to the patient's ability to treat the condition. The numbers measure both the state of the body and the patient's compliance with medication and everyday habits that are thus transformed into matters of 'lifestyle'. The audiometer figures hearing as a mental capacity and a private experience, and events in the past that may have affected the ability to hear are not seen as a matter of 'lifestyle', but rather as part of the patient's 'life conditions'. From the perspective of measuring devices, certain features of the body, the patient experience and everyday habits are related to form partial versions of the medical conditions.

TRANSFORMATIONS OF PATIENT EXPERIENCES

In some consultations, measurements and patient experience were unproblematically aligned. Hanne, a woman in her sixties came into an ear, nose and throat clinic for a hearing test. She had previously had her hearing tested at which point the doctor and Hanne agreed that she did not need hearing aids yet. When I met Hanne seven years later, she was convinced that she did not hear well, and her doctor observed from the test that her hearing had significantly worsened, and suggested that she get amplification. Hanne agreed, and the doctor immediately brought out some hearing aids for her to try out. The diagnosis and treatment decision were made within a few minutes, and Hanne's experience, her doctor's measurement and the available solution were all aligned. In another case, I was in the clinic of a general practitioner, where Hans had come in for a diabetes review visit. While the doctor was busy with paperwork, Hans explained to me how he was diagnosed. He had come in with symptoms of blurred vision and constant thirst. A blood sugar test showed that his HbA1c was above 30 mmol/L and he was sent to the hospital the same day for insulin treatment. In both situations, the problem described in the patient's account, the tests conducted and the available treatment unproblematically coincided.

In her study of the different practices for knowing arthrosclerosis across a hospital, Mol shows that each practice produces a slightly different version of the disease (2002). These different practices do not attract attention as long as they coincide. But when they conflict, and a physical examination and history taking contradict each other, diverse practices of enacting the disease are unbracketed (ibid:51). The disease enacted in the clinic is then twofold: the physical examination and the interview. Each time a conflict occurs, reality multiplies, Mol argues, and part of her project is to study the multiple enactments of atherosclerosis and the 'remarkable achievement' of making these multiple objects 'hang together somehow' (ibid:51,5). Attending to conflicts, she observes, brings the practices for knowing out in the open. This observation also applies to my material. On the one hand, in the cases I mentioned above (Hanne and Hans) are situations, where diverse enactments of the medical conditions coincide, we learn very little about the practices for knowing the diseases. On the other hand, when focusing on consultations where diverse enactments of the medical conditions contradict each other, I will be able to study the work it takes to account for the differences and make them hang together in the practical assembling of *one* condition. What is otherwise opaque is made observable when conflicts arise. In the following, I want to explore, how doctors and patients make sense of test results and in this process enact versions of the conditions by electing and categorizing certain events and experiences as relevant to the activity in which they are engaged. I suggest that not only are patients and doctors moving between the objectified body and the experiencing subject, but also that these two orientations to the body and its ailment reciprocally elaborate each other.

Relating blood sugar levels to lifestyle

In diabetes care, blood sugar measurements not only evaluate past activities but also transform them into a causal relation to the blood sugar. One time, when I was in a clinic north of Copenhagen, Carsten, who had had diabetes for some years, came in for a review with his general practitioner, Mogens. Carsten complained a bit about the difficulty of making lifestyle changes, and then they looked at his test results:

> Mogens: If we look over the course of time … (*reading from the computer screen*) you started on 7.9, you can say that that is close to 8 and that is really high. Then you have been down at around 7.2 and 7. Now you are stable at 7.5, right?
>
> Carsten: Yes.
>
> Mogens: So, if you could get down, just below 7, between 6.5 and 7.
>
> Carsten: When was that?
>
> Mogens: No, you have not been, but...
>
> Carsten: When was it?

Mogens: That you were at 7?

Carsten: Yes.

Mogens: That was in August last year.

Carsten: What did I do in August that I do not do now…?

Mogens: I do not know.

Carsten: I will have to find out.

Mogens: Yes.

In this consultation, Mogens and Carsten orient to the numbers as having come about as a result of particular activities. However, what Carsten did not know what he had done that would explain the numbers. Paradoxically, he had the authority to know what he had done, but it was not immediately knowable to him. It was not simply a matter of remembering, but knowing what he had done and how he had done it– in which some actions can cause spikes or drops in the blood sugar. Mundane activities are sought to be transformed into causes of blood sugar, though this is not how they are first known by the patient, as we saw with Henrik.

In the following consultation, Bitten came in for a review with her general practitioner Mark. He had measured her short-term blood sugar, which he categorized as high (no numerical value mentioned) and they were seeking the reason:

Mark: Did you have breakfast this morning?

Bitten: Err; I was just about to start. I took a bite of an apple and then threw it away immediately, because you forget, it is automatic that you just take…

Mark: Okay, yes, yes... Okay so we cannot tell – It is not that.

Bitten: No it is not, it was just a single bite.

Mark: So you are not fasting as you usually are, that is fine.

Bitten: Yes, well I am fasting, because it was so little, and I spat it out again.

Mark: Okay, okay. Well, then you are fasting... Because your blood sugar is higher today than it used to be. You are usually around 6.6 and alike, but today it is-

Bitten: I have been walking from home today.

Mark: So it is just higher today. . Anyways, it is a single blood sugar.

Bitten: But, but I ate something – I had a nice dinner yesterday.

Mark: Oh, maybe that is it.

Bitten: Yes, yes, and there were cakes and such, it was sort of sweet things.

Mark: Yes. Okay, that might be.

Bitten: I rather think it is.

Mark: Yes, yes.

The first two activities of fasting that morning and walking to the clinic did not explain the elevated blood sugar value, and were not relevant for their inquiry so they kept searching for an activity that could explain the elevation. Only actions that were consistent with the measurement were foregrounded, while those that did not were ruled out.

These two extracts show that measurements shape how the patient's experiences are 'taken' in the clinical encounter. The patient's account depends on the type of test and its result; whether the short-term or the long-term blood sugar is measured, and whether the number is high or low. When evaluating the long-term sugars, as in the previous case, the patient is expected to account for actions and habits over the past months. Accounting for the effects on the short-term measurement, in contrast, is a matter of here and now; it foregrounds what the patient had done that morning or the night before. By relating one activity to the number, it stands out as more relevant in picturing the patient's efforts, and the measurement guided a reading of Bitten's efforts that did not include her walking to the clinic and throwing away even a small piece of apple to be compliant with the fasting. In this case the measurement foregrounded her failure and left out the success. The test result guides, marks and sorts relevant activities to take into consideration; it figures a particular way of seeing and transforming the patient's experience. In Goodwin's terminology, certain activities are highlighted, marked and made salient in a complex perceptual field, as other phenomena recede into the background.

In the following consultation in a clinic outside New York City, Rita was in for a review and her nurse practitioner Karen had measured her short-term blood sugar at 98 mg/dl; at home that morning, Rita had measured it at 87 mg/dl[4]. The difference between the two measurements required Rita to account for numbers:

Karen: Okay, I saw that your blood sugar was 98 this morning. How often are you checking your blood sugar?

Rita: I do it every morning.

Karen: Every morning before you eat?

Rita: The first thing - this morning first in the morning I got it like 87.

Karen: Okay.

Rita: And this is because I already had some, you know something. I had a cup of coffee. Decaf. A slice of white bread, and with a very light butter

Karen: Mhm.

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[4] In the USA, blood sugars are measured in mg/dl as opposed to the Danish measure in mmol/L (see page 43).

Rita: And then this morning I took a little bit of regular orange juice. Normally I don't use regular orange juice but I was out of my other orange juice.

Karen: Mhm.

Rita: And I just feel like having a little bit of orange juice. But like, like this, not a cup, not even half a cup.

Karen: Just a couple of sips.

Rita: Yes.

Karen: Okay.

In her account, Rita did not only reply to the question about how often she measured, but gave an elaborated account about what she had eaten and drank in the morning. In doing so, she made a presentation of herself as a responsible person who was careful about what she ate. Every food item was described in a manner that highlighted its nutrititional benefit: 'decaf', 'very light butter', 'not even half a cup'. She demonstrated that she knew how to follow cultural norms about healthy living and wisely moderate her desires, noting that she 'felt like' orange juice, but only had a little. She took part in transforming her eating into lifestyle activities with effects on her test results.

Learning what it means to eat and move

The patients with diabetes that I met did not always know how to transform their everyday habits into their effects on blood sugar. In one consultation the transformation was explicitly presented by the doctor as a learning process. The patient, Niels, had just been diagnosed, and during the encounter they went over his home measurements and talked about what these numbers meant. In the following extract, Niels had brought out his notebook to show his doctor, Mogens.

Mogens: You do already have it under control, right?

Niels: It looks fairly reasonable, right?

Mogens: Yes, yeah. So you have one (*pointing in the book*), you have three values, that reveal that you have a sugar problem; otherwise the rest are already down.

Niels: Yes.

Mogens: This is an exercise you do to get experience and know, kind of say, what does it mean to eat, right? How much, how much does it rise?

[…]

Mogens: Did you do anything special for this?

Niels: I take those pills.

Mogens: Yes, but did you do anything else?

Niels: No.

Mogens: That is, you have not done anything special; been out running or..?

Niels: No, that is, we have been working hard on the weekend with the apple sale, and all that, right? It is a lot of exercise; you are really tired when you get home.

Mogens: Yes, yes.

Mogens oriented to the measuring as a way of gaining experience with the effects of food on blood sugar; the number was a way of knowing the relation between food and blood sugar. The low numbers that Niels presented meant that they were inquiring into what he had done to get these numbers; it was a search for efforts. Niels had taken the medication, but Mogens was searching for another reason in something 'special' that Niels had done. In this light Niels' account about his job selling apples was interpreted as 'exercise', since it involved 'using a lot of energy'. Finding out what qualified as exercise and 'having it under control' involved reading the numbers as well as inquiring into everyday activities at home. The activities that align with the number are figured as part of the patient's 'lifestyle', whereas Niels' not having done anything 'special' is left out. An important observation here is that there is a mutual construction of numbers and patient accounts. Above I noted that numbers depend on knowing what the patient has or has not done, but they also guide the way in which previous actions are examined and made relevant.

In the following, we will see that what is taken as 'exercise' may relate differently to the medical evidence. Pedro, who like Niels was newly diagnosed, explained to his nurse practitioner Karen, how his high and low numbers were related to his work and sleep patterns. He was accounting for the high numbers he got in the morning as a result of sleeping all night, unlike his low numbers in the evening, after having worked all day:

Pedro: In the morning it's, it's always higher, because I always check it when I come from work too.

Karen: Okay.

Pedro: And it's like super low.

Karen: Okay so what's your highest number?

Pedro: The highest is 180.

Karen: Okay.

Pedro: And my lowest is like 123 around there.

Karen: Okay so, I mean a normal blood sugar is like between like 80 and 140.

Pedro: Mhm.

Karen: I like it between 80 and 140. So you're a little bit higher, when you get to the 180.

Pedro: I'm guessing it's because in the morning when I wake up, well I don't wake up early, but my body's resting...
Karen: Yeah well.
Pedro: And then when I'm at work, I'm always constantly moving around.
Karen: Are you exercising?
Pedro: Well at work I do a lot of exercise because I move a lot of boxes and all that stuff.
Karen: Oh, okay.

When Karen observed that Pedro was not within the normal range, he explained this by sleeping at night, whereas the lows were explained with his ‘constantly moving a lot’. When Karen asked if he was exercising, she suggested that what he called ‘moving around’ did not qualify as exercise, and he ought to do more to reach the normal blood sugar values. The high numbers meant a search for some real effort to change his medical condition.

In this work doctors and patients search for particular activities in everyday life that stand out as explanations to the blood sugar numbers measured. As we saw in the first consultation, only the patient knows what he has done, and he is expected to be able to report on it. But knowing what he has done as ‘exercise’ is a collaborative activity guided by the measurement in which high numbers encourage a search for failures and low numbers a search for efforts. As a consequence, the patients’ accounts about their doings also involve highlighting certain features and transforming them into categories of concern for the medical profession.

Coding hearing experiences

Most of the hearing care consultations that I observed included a history taking about the patient’s experience of his or her hearing loss, as we saw with Svend. Where the diabetes care transformed eating and moving into causes of spikes and drops in blood sugar values, the coding of hearing experience was a matter of adding more knowledge about the hearing loss. As Anna pointed out above, hearing takes place in the brain and the history taking drew a picture of how the patient experienced his or her hearing. In the following consultation, Allan had come in to see George, his ear, nose and throat doctor, because he was suffering from constant headaches, pressure on his forehead and had a feeling of stuffiness. As part of the examination, his hearing was examined. When they had talked about his other symptoms, George brought up Allan’s hearing:

George: Has your hearing gotten worse over time?
Allan: I do not think so, my wife thinks so.
George: Do other people notice?

Allan: Well because I'm constantly saying 'excuse me?', 'what?', 'ehm I didn't hear that'...

George: TV louder than usual?

Allan: She complains about that too...

George: And what about restaurants?

Allan: Restaurants are difficult.

The work here and in many other consultations was a matter of documenting the patients' experience of how well they manage in particular situations, most often including how they adjust the volume on their TV, if they can hear the phone ringing, if they are able to have a conversation on the phone, and if they can converse in a setting with background noise. In other words, the doctors used another device for measuring to supplement the audiogram; by systematically asking the patient to assess his or her difficulties in particular constellations with technologies and other people, they selected and transformed the patient's experience in his or her professional context. The patient was thus assumed to be able to recognize and identify hearing problems and evaluate the amount and extent of problems caused by diminished hearing. The hearing condition was addressed as a matter of measurable loss of audibility, contextualized with the patient's observations of the problem under designated conditions. This emphasized the individual and personal aspects of hearing loss, and located it in the body of the hearing-impaired person, by whom it was sensed and experienced.

However, the doctors did not always confine to pre-defined situations; some took the patient's everyday life as the starting point for finding out if the hearing caused problems, as we see in the following exchange:

Anna: When I have looked at your hearing curve, then I can also say, there certainly are some of the treble notes, that are up in the very high frequencies, that you hear really poorly, but on the other hand there is a large part of the sounds that you do hear – actually normally. So we might say, that you are a – what I would call a borderline case; how eager should one be about getting started? So therefore I am going to ask you a bit about how you experience, that you do not hear as well as you used to. For example, let's take an ordinary day with your wife. Can you hear the alarm clock, if you have one?

Børge: I have an inner alarm clock.

Anna: You have an inner alarm clock. Okay, so that does not count hearing wise. So I want to know when you go around having a normal day, including morning coffee, newspaper –are you constantly having to say 'what are you saying?' 'excuse me?'

Børge: No.

Anna: And she has to repea-

Børge No she does not.

Anna She does not.

Anna. So that is, on an everyday basis, you are doing fine?

Børge Yes. But this is what I would like to tell you,

Anna: Yes?

Børge: What you said about the high tones.

Anna: Yes.

Børge That's what the other ear doctor said too; your hearing is fairly normal.

Anna: Yes, precisely.

Børge: - but you cannot hear the cicadas.

Anna: No, exactly.

Børge: *That* is what I am incapable of.

Anna: Yes, and the cicadas and the high frequencies they are also part of our everyday sound picture.

Børge: Yes it-

Anna: And they add some nuances, and it kind of makes you able to hear some words better if you have all the notes in the high frequencies, than if you do not have them. So even if you are not listening to cicadas, they are a little important when you need to understand speech. So what I would like to ask you is, do you have- when do you notice that you do not hear so well? Do you turn up the TV louder than your wife?

Børge: No.

Anna: You do not.

Børge: No.

Anna: What then, when it is teeming with children and grandchildren, will they say: 'Grandpa you cannot hear anything'?

Børge: No.

Anna: No.

Børge: I do not think so. I do not think so.

Anna: They do not. Who is it then you-

Børge: I said that a remark might be dropped occasionally, right?

Anna: Yeah, yeah.

Even if Anna started out generally, she soon asked Børge if he could hear his alarm clock and if he had to ask people to repeat themselves. These situations and the patient's evaluation of them as either problematic or not, was a way of finding out if they should start treatment. By using another doctor's evaluation, Børge pointed out that he only had difficulties hearing high notes, as in the rare event of listening to cicadas; a situation that did not form part of his everyday life in a suburb of Copenhagen. In qualifying her questions, Anna informed him that high notes are important for understanding speech, and suggested additional situations that might cause problems. Measuring the extent of problems of particular situations and coding those situations as either ordinary or extraordinary worked as a way of engaging a discussion, not only about his hearing, but also what made for everyday hearing situations.

In most of the consultations I witnessed, the patient provided an evaluation of the problem when asked by the doctor, but the following consultation reveals a complexity in knowing what a hearing problem is. Connie was in her seventies and had come in for a hearing test at her daughter's urging.

Sebastian: Well, you said you have had problems for several years?
Connie: Yes, I believe so, but I did not want to admit it.
Sebastian: Yeah.
Connie: I was not that old, I would say.
Sebastian: No, no – and your children were complaining?
Connie: Yes.
[…]
Sebastian: But do you feel you have a problem now?
Connie: If I do..? Ha, well I still do not want to admit it, I say that they talk too softly.

Connie was uncertain about when her hearing started to worsen. She kept the possibility open that it was not a matter of her not being able to hear, but of people around her not making themselves understandable. This piece of conversation indicates that the way in which patient experience was usually 'taken' in clinical encounters, to be transparent to the patient, left the patient with the task of figuring out whether a communication problem should be ascribed to his or her inability to hear or to other causes.

The patient's skilled coding

The stereotype hearing situations are not directly pointed to as something the patient needs to learn, as we saw in diabetes care. However, being familiar with the stereotypic situations in self-reports allows the patient to provide a presentation of his hearing that transforms it to a hearing problem in the professional discourse. By providing a relevant representation of the hearing difficulty, the patient shapes it to fit with the notion of hearing impairment. In one consultation, Mark who was a man in his forties came to see Sebastian, his ear, nose and throat doctor. He had already seen an audiologist and had had his hearing tested. Early in the consultation, Sebastian asked Mark about his hearing:

Sebastian: But, the short story is that you have become, er, it has gotten worse?

Mark: Well, I can hear fine when we are standing here talking...

Mark points to me, referring to the chat we had while the doctor was out of the room.

Sebastian: Yes, yes.

Mark: But I have problems with- in dinner parties in particular.

Sebastian: Yes.

Mark: When I am sitting at a table and talking, and there are people sitting and talking from across the table.

Sebastian: Yes.

Mark: Then I have a hard time following-

Sebastian: Okay, so when there are more people together, that is it.

Mark: Yes, I think so.

Mark struck me as skilled in categorizing his hearing difficulties in professional terms; having problems in ‘dinner parties’ is a typical example of ‘talk in noise’, which was something the doctors always asked about. He demonstrated that he knew the vocabulary and was skilled in coding his hearing experience by identifying a particular situation and evaluating it as problematic.

In her study of women in treatment for infertility, Cussins argues against the stance that patients are made passive and alienated, when they are treated as objects for physicians and technologies (1998). She shows that being enrolled in fertility treatment requires women to take an active part in transforming themselves into objects for treatment. This does not only happen in the clinic during physical examination, but also prior to it, as they monitor themselves for sign of ovulation and menstruation or take their temperature in the morning. In either case, the women are working to increase their chances of conception, and ‘the physician is a point in the chain through which access to the techniques is mediated. The patients do not so much let themselves be treated like objects to comply with the physician as comply with the physician to let themselves be treated like objects’ (ibid:178-179). In other words ‘agency requires objectification’, since these women depend on being the object of modern medical technology to get pregnant (ibid:166).

In my material, only few patients were, like Mark, using the objectification of their bodily experience to gain access to treatment. Many others worked to avoid treatment technologies. Independent of their desire for treatment however, they actively engaged in situated transformations of their body, experiences and history, moving between subjectification and objectification of themselves.

EPISTEMIC AUTHORITIES

Using the concept of ‘epistemic authorities’, I want to discuss how doctors and patients claim the right to know certain features about the health condition. Along the lines of Good’s ‘folk epistemology’, we usually think of doctors as having epistemic authority of medical knowledge, test results and diagnosis. The patients, in contrast, have epistemic authority on pain and other sensory experiences as well as past activities at home. With my analysis of knowledge practices in the clinic encounters, I have demonstrated that the body as an object of knowledge and a subjective experience emerges through interplay of tools, medical practices and evidence. Since numbers and patient experiences thus stand in a mutually constitutive relation to each other, the division of epistemic authorities is not sharply drawn. In the following, I will examine how epistemic authorities are claimed in the clinical encounter and compare the different versions of what it means to be a patient in the two disease areas.

Empirical epistemology of hearing

As we have seen, patients in the ear, nose and throat clinic are interviewed by their doctors about their experience of hearing and ways in which it causes problems. During the process of selecting and evaluating problematic situations, the patient is oriented to having epistemic authority of the hearing sense, because it ‘takes place in the brain’ as Anna explained. However, the audiogram sets the frame for questioning and guiding the inquiry, as when Anna observed that Børge’s hearing was borderline and said they needed to find out how much problems he was having. In this consultation, Anna claimed authority to translate what it meant to have a loss in the high frequencies, but only Børge knew its impact on his life. We now return to George and Allan, as they went over the results of the hearing test, and George explicitly pointed to the difficulty of demonstrating a hearing loss with an audiogram:

> George: I don’t know what your interests are but ehm (*George takes out a print of the audiogram and shows it to Allan*) you know, I suspect-
>
> Allan: I don’t know what that means; not good?
>
> George: N-yeah this is not- this is similar to mine, and I told, you I wear hearing aids.
>
> Allan: Okay.
>
> George: But, the difficulty is, one to one you’re fine.
>
> Allan: Yes.
>
> George: Like now.
>
> Allan: Yes.

George: But you get background noise, you have a problem because, we depend upon high frequencies to discriminate word endings, so when you drop the whole curve, it gets worse.

Allan: Yeah.

George observed that it is hard for him to prove his point with the audiogram, the 'difficulty' being that in this same moment Allan's senses told another truth: his hearing was fine. By drawing on his own situation and choice, George demonstrated what he thought was the right thing to do. However, he did not orient to this as a medical advice, but as a personal preference. Much like Sebastian, who told Svend that hearing loss was a question of feeling inconvenienced by his hearing loss, George refrained from making a medical judgment about a need for treatment, and later told Allan that getting amplification is 'an obviously personal decision'.

I observed several consultations, where patients had their hearing tested because relatives had encouraged them to go or because the doctor included it as part of an examination of other symptoms, and not because they believed that there was a problem. Lisa was one such patient. She had come in to see her ear, nose and throat doctor, George, for vertigo, which had caused her to fall when she woke up one night and got out of bed. The test of her hearing was made as part of the examination. Lisa had a hearing test made some years earlier too, and both tests showed what the audiologist called a 'good solid moderate hearing loss'. After completing the test with the audiologist Lisa came back to discuss the results with George:

George: The other question is about your hearing. You wanna know anything about it?

Lisa: Not right now *(laughs)*, not right now.

George: I wear hearing aids. Here is my answer and this is not, no kidding here. Let's say you wait 10 years and your hearing gets much worse, you're gonna have a more difficult time adapting to hearing aids.

Lisa: No I am not going to wait ten years, but I am gonna wait for right now.

George: How much trouble do you have with your hearing?

Lisa: I do not think I have that difficult problems. It is just that, when I turn up the volume on the TV, my kids tell me I am deaf, but when we're in the car and they turn up the volume where I am becoming deaf, I yell at them, and they are not children anymore.

George: What, what about if you're in a restaurant, or with background noise, you have some difficuty understand what is being said?

Lisa: No, I haven't yet. It is funny how when I turned 40, my ophthalmologist said I'll probably need bifocals, I am now 62, and I am just starting to have difficulty with seeing the fine print on things -

George: You're lucky.

Lisa: - which I have been able to see until last week actually. So I, I do watch these things. I have my eyes checked every year. My hearing is what it is. If I really feel that it is going to be severe, then of course I am going to do something about it. I am not vain, because if I was, I would not be gray.

In this conversation, Lisa provided an assessment of her hearing and by comparing her own behavior to her children's, she depicted her own as more normal and benign. With the story about her ophthalmologist, which demonstrated that she knew better than the health care professional, she further supported her epistemic authority of her senses. While the medical evidence showed that Lisa had moderate hearing loss, George did not use the audiogram to argue that she should get amplification, but instead asked her, how much trouble she was having. Lisa claimed authority to know her senses as well as her motive, as she rejected the implication that she was afraid of appearing elderly.

Across the hearing consultations I saw, the doctors claimed the epistemic authority of the medical evidence, but it did not tell the whole 'truth' about an impairment, which was also taken to be a subjective matter. In consultations like the one with Lisa, where the audiogram showed a significant loss, I did not see any doctor use the medical evidence to prove what the patient experienced was wrong. There were though one consultation (to which I will return in chapter five), where the audiogram showed perfectly normal hearing, and in this case, the doctor told her patient that he was not using his good hearing properly, ascribing him the responsibility for listening, since he was capable of hearing. Apart from this one exception, a distinction was rarely made between hearing and listening. When doctors asked their patients if they had hearing difficulties, it was left to the patients to interpret when they were not able to hear and if this was a problem for them.

Counteracting diabetes

In diabetes care, the patient was oriented to as knowing his or her own actions and being able to account for them, and to be in control of them with the ability to act differently. In the consultation with Henrik, we saw that he was held responsible for high numbers and needed to 'do better'. In the following consultation, Hans, who had had diabetes for five years, came in for a review with his general practitioner Jørn. Hans started by talking about, how he 'won' over the doctors by taking action, losing weight and being able to stop most of his medication, but moved on to demonstrating his skills in measuring and evaluating numbers:

Hans: I started the first two months out there *(at the diabetes hospital)*. And I was prescribed 16 pills a day.

Jørn: You had 16 pills.

Hans: Yes, I got for cholesterol, hypertension and so on. And my question to them was, if I had to take this for the rest of my life. And they told me yes.

Jørn: They said yes.

Hans: Yeah. Then I said, just for fun; now I have to see you for six months, but we can bet a bottle of whisky, that when I am set free from this hospital, I will have lost the 23 kilos, and then I will be within the normal range. And I won that bottle of whisky. So I am only on an anticoagulant tablet.

Jørn: And you are not interested in taking as many pills, as you did back then. You would rather not have that?

Hans: No, because in the long run, the kidneys cannot tolerate all that medication.

Jørn: Well, they do not harm the kidneys; I don't think you can say so.

Hans: Well, there are side effects to all treatment.

Jørn: Yes, that is true. But they do have some beneficial effects too; they will keep your cholesterol low, and if you have high blood pressure, they will keep that down too.

Hans: Yeah.

Jørn: They will keep the blood sugar number better regulated than what you can do with diet alone.

Hans: Yes, that is correct, but I am feeling quite fine.

Jørn: And what blood sugar values do you get, when you measure it now? Is it always below ten?

Hans: Yes. Well, I do for example - I have to do it once a week.

Jørn: Once a week, yes.

Hans: And I change between days. The first one I will take on a Monday, and the next week I might do Wednesday. And then I do morning, midday and evening.

Jørn: Yes.

Hans: And that is to say, I measure two hours after breakfast, two hours after lunch, and two hour after dinner.

Jørn: Yes.

Hans: And it is between 5.6 and 7.2.

Jørn: Okay, well that is of course fine.

Like Lisa, Hans accounted for his ability to take care of his own health, but there are significant differences in the sources of knowledge they put to use. Hans first demonstrated that he proved the doctors wrong by losing weight and being able to go off his medications; he was able to change his lifestyle and thereby his diabetes. His doctor, rather than acknowledging this, transformed it to a personal preference for not taking medication, and argued that there are medical reasons to stay on medication. When Hans replied that he ‘feels fine’, Jørn turned to the numbers, as the source that would tell them if he really *was* fine. Rather than just telling what his home measurements showed, Hans produced a detailed account of *how* he measured. He provided a structured description in the form of a list of days, time of the day and number of hours he waits after the meals. He also provided very precise numerical values of his measurement that were well below the limit of 10 set by Jørn. As Sack argues, we often sometimes use precise numbers to demonstrate the precision of an event or action (Sacks 1988). Hans thus demonstrated not only that his blood sugars were within the normal range, but also that he was adept in measuring, managing and controlling his diabetes.

Comparison of the cases of Hans and Lisa illustrates the different authorities that patients may claim. Lisa could claim to know the extent to which her hearing caused problems and if her hearing loss had become ‘severe’. Hans claimed authority by demonstrating that he could lose weight and measure his numbers accurately and with good results. The epistemic authorities relate closely to the rights and obligations of the patient. Hearing is primarily a sensory and personal issue, to be known by the patient. With Svend, we saw that hearing loss caused by working in a noisy environment without ear protection was non-problematic, and the possibility of changing habits was rarely addressed. There is not the same obligation to take care of hearing problems, as I saw in the diabetes clinic. The possibility of preventing hearing loss from worsening worse or ‘treating’ it with behavioral change is backgrounded in the clinical interactions.

While we may commonly find it quite obvious what it involves to be a patient in a clinical encounter, the counterpointing of diabetes care and hearing care shows that what the patient can claim to know and is obliged to do vary substantially. In comparison, the diabetes and hearing care rob each other of their immediate obviousness, and it is clear that what it means to be a patient is a truly local phenomenon.

CONCLUSION

In this chapter I have demonstrated that medical conditions, rather than being ‘given’ prior to clinical interactions, are ‘taken’ through situated inquiries. I first observed how measurements are carefully and collaboratively conducted by patients who actively constitute themselves as objects for clinical investigation and doctors who perform tests that transform physical functionality or blood samples into materialized representations. In the process, the measuring devices that they use mediate and enhance particular features of the body's ailments. Even thought the audiograms and test results from the blood tests provide a certain objectiveness they are not treated as mere conclusion or end points of the inquiry of the medical conditions. The medical evidence raises new questions and doctors and patients actively engage in meaning-making interpretation of diagrams and numbers.

As part of this meaning-making work, I have explored how different sources of knowledge, including the test results and the patient's accounts on sensory experience or everyday lives at home are related. Certain explanations are offered before the test is conducted, and when the result is made available, it guides the representation of the patient's experience. A 'solid moderate hearing loss' made George ask Lisa if she had any problems with background noise, whereas a 'borderline case' like Børge started an exploration in the borderland of normal hearing and ordinary needs and abilities. A low blood sugar made Mogens and Niels search for activities that had burned off energy, whereas an elevated short-term test made Bitten and Mark search for recent consumption of high-calorie food. Activities of the diabetes patients are set in a causal relation to the test result, whereas the experience of hearing loss is categorized in stereotypical hearing situations and evaluated with a subjective measure of 'feeling bothered' to supplement the mapping of the hearing loss. In diabetes care, everyday life is thus transformed to a matter of 'lifestyle' and ongoing treatment, while in hearing care everyday experiences are made into a resource for knowing the sensory experiences of hearing and amount of trouble it causes, and whatever behavioral causes there may be are often treated as a matter of 'life conditions'. Consequently diabetes and hearing patients have very different authorities to know and obligations to act in the interactive assembling of each medical condition.

Both the objectively measurable medical condition and the account about the subjective experience emerge through careful interactional work. My conclusion is not a rejection of the distinction between the body as an *object* for medicine and an experiencing *subject*, but a persistent attention to how such phenomena are practically built in interactions among people, practices and technologies; an attention to how people accomplish what they treat as real.

In this chapter, the production of the medical conditions have been situated in the clinic, where closed doors cut off the world outside, and make for a remarkably quiet place where hearing problems rarely arise in conversations, and where people become 'patients' as they relate to their disease and doctor. In the following chapter I displace myself to the home setting to examine how the medical conditions are produced through practices outside the clinic.

CHAPTER FOUR

SITUATED CONCERNS

In this chapter, I move beyond the closed doors of the consultation room to explore how medical conditions are dealt with in everyday life at home. It may look as if I am reproducing the classic distinction between a *disease* that is known and explained by biomedicine in the professional sector and the *illness* as a personal, psychological and social response to the disease taking place in the popular sector (Kleinman 1980), and hence drawing a dichotomy between the body as an object for medical knowledge and the body experienced by a subject. My aim, however, is the opposite. I have demonstrated that the body and the conditions are not 'given', but rather 'taken' in the clinic. They emerge as the result of an inquiry, directed towards the practical purpose of a clinical encounter; to locate and solve a medical problem. They are situated in a professional context with a historically developed practice for seeing. In this process medical evidence and patient experience emerge in particular shapes, and mutually elaborate each other. Rather than a dichotomy between the body as an object for clinical knowledge and the body as an active and experiencing subject, there is a mutual production of the two in the clinic. The present chapter continues this approach. By foregrounding practices, I explore how the medical conditions are practically produced in everyday life, not as a psychological and social response, but as embodied enactments.

The move I make is thus a matter of displacing the question about *how* the medical conditions are inquired and dealt with in the clinical context to the context of everyday life. Gubrium and

Holstein argue that a displacement across medical and family contexts 'allows researchers to view mundane reason and everyday practices in light of alternate social environments and practical purposes at hand. This renders everyday practices more visible by virtue of the possible contrasts that emerge across contexts' (Gubrium and Holstein 2012: 95). Following this line of though, the contrast between the clinic and the home and the differing practical problems people engage in in these contexts will render specificites of each practice more visible. Where Kleinman's conceptualization of a health care system divided into sectors represents each setting as fundamentally different from the others, I suggest symmetry between the clinic and the home, as they are both sites of mundane practices and social interactions. In each site the medical conditions emerge from practical inquiries (Dewey 1929, 1925), and in each site they are something being 'done' (Mol 2002). Shifting to the home means that other actors are interacting and other practical purposes are at stake, yet comparison with the clinic may reveal how hearing loss and diabetes are done differently.

The starting point for my analysis is the paradoxical invisibility of both conditions. In the clinics, the medical conditions were rendered visible through professional practices of measuring and coding. In the homes, I was puzzled by not being able to observe hearing difficulties when I spoke to people with hearing impairments, and I met many people with diabetes who were struggling not to forget their condition, which was known as latent future risk. This bewilderment came to steer my empirical curiosity as I explored the ways in which the conditions emerged as problematic and in need of attention and intervention.

The analysis is structured in three steps. In this first part I explore how the medical conditions emerge in problematic situations and how they are handled. This part is inspired by Mol's praxiographic approach. Empirically I draw on material from interviews, diaries and auto ethnographies. I follow Mol's recommendation and treat people as their own ethnographers, as they observe enactments of the medical conditions, while I am not present. In this way I can explore how living with hearing loss and diabetes is 'done'.

There is, however, a limit to how far this analytical approach allows me to understand my empirical material. In the second part, I observe that events do not simply occur in people's lives, but are 'taken' and made part of a meaningful account about the medical condition. I turn to the concept of 'marking' medical conditions, as a mundane practice for assessing and relating everyday events to a progressive medical condition (Gubrium et al. 2003). In the clinic, the medical conditions are produced as certain features are 'taken' and related to each other for the practical purpose of constructing a solvable problem, likewise when people are going about their everyday lives; they select certain features and make connections in relation to a myriad of practical concerns. In Mol's notion of practice, the praxiographer attends to 'practicalities, materialities and *events*' (2002:13, author's emphasis), while leaving behind matters of meaning and interpretations. This analytical focus attends to what people *do*, not to how their doings are directed at certain objectives; dealing with something that matters and appears problematic to somebody. That, however, is crucial to understand my empirical material, and I suggest another notion of practice, in which 'events' and people's practical handling of their medical conditions is a matter of 'directed action'; people are inquirers who are concerned about something that mattes to them (Dewey 1925). With the concept 'situated concern', I argue that practical productions of medical conditions are part of ever-changing and uncertain circumstances, in which people deal with problematic situations (Whyte 1997). I thereby attend not only to *how* people act in relation to their medical conditions, but also *what* they strive for and endure (Dewey 1925:18). I argue that people engage in handling their medical conditions only because they are concerned about something that matters to them (Whyte 1997).

As I argue that problems emerge *in situ*, it seems inevitable to observe that the stories people told me are not privileged accounts, but are situated within a particular context. In the third and last step of my analysis, I will turn to empirical material of people interacting, not only with me, but with each other. I show that interpretations are not stable, but changeable and negotiable in a social context. The material I draw on differs between the two conditions. In the case of hearing impairment, many of the people I spoke to were accompanied by a spouse. In my conversations with the couples, I observe that interpretations of the medical condition are negotiated, and that recognizing as well as dealing with hearing impairment are social matters. Most of the people with diabetes that I interviewed were unaccompanied, but based on my workshop data (where diabetics met with strangers who were also diabetic), I show that the experience of this condition is embedded in an interactional process of interpretation and transformation, and not a sole individual's response to disease (Gubrium and Lynott 1987).

'I DO NOT FEEL IT'

When I visited people in their homes, I was quickly puzzled about how rarely the medical conditions seemed to emerge as problematic. An experienced researcher had told me that it had been eye-opening to meet up with hearing-impaired informants in cafés to see firsthand the difficulties of keeping a conversation going against the background noise of other people talking and eating. I never found myself in the presence of such problematic situations, even though I occasionally talked to people in traffic and at cafés. Of course, this difficulty was also the very reason for my study. We were working with 'pre-users' to find out how they related to their medical condition when treatment was not an obvious necessity. Most diabetes patients I spoke to were fairly well regulated and rarely felt unwell, just as the people with hearing loss did well in many situations. I soon learned that not only I, but also people I studied were disturbed by the invisibility of their conditions. As Stephan, a sixty-year-old man living in Brooklyn with his wife and son explained to me:

> I am not so aware of it [the hearing impairment], and I am only aware of it in particular contexts, as I say, in crowds and what I hear basically just drown, I cannot break it up into sounds. Now, in my work environment - I work in an office in which there are eight desks, and the person who is the furthest from me, I am aware that he very often has said something to me and is surprised that I have not answered him, but if I am in a cocktail party I am aware of it, I can feel it, but in that context I do not. I don't feel that I am not hearing, it seems normal to me, but then I will realize that Stan has gotten up from his desk again and said 'Stephan, did you hear what I just said?' and I will say 'No'. So the louder the sounds, the more I am aware of the reduction in my hearing. In a more normal environment, like right now, I don't feel that there is any degradation in my hearing.

Stephan distinguished being able to sense his difficulty with hearing from being made aware of it by other people. What to him appeared normal was sometimes treated as abnormal by people around him. They repaired breakdowns in communication, and only then did he become aware of the disruptive consequences of his hearing impairment. The fact that he only felt his hearing loss to some extent, while it was mediated by his surrounding in other situations raised an uncertainty, not only about his hearing, but also about his ability to feel and notice the consequences of his hearing loss. While he was able to feel the impairment when he could not 'break it up into sounds', he did not feel it when it was quiet and he did not hear what other people said.

Karsten, like Stephan, was not always aware of his hearing impairment. What caught his attention, he told me, were his children telling him the TV was too loud, and his wife complaining that he had not heard what she was saying. When I asked if he had problems outside of his family, he explained:

> I would imagine, but I am not very conscious of it. Not yet. I expect that when a lot of people talk, I will find that I am not too keen on following the conversation too far away, because I cannot hear. That is the problem with hearing impairment: you get used to your radius of operation getting smaller, and you take it for granted that it is like that.

One thing was that his 'radius of operation' got smaller; which was what many people I met explained; they heard fewer sounds, they could not hear from a distance or against background noise. The problem Karsten pointed to, however, was different: he worried that he did not notice his world getting smaller as he became accustomed to his impairment. His hearing impairment was dubious, not only because of the gradual degradation of what he was able to hear, but also because his notion of what was 'normal' subtly changed and possibly diverged from what other people's thought was 'normal'.

The people I met with diabetes were already diagnosed, and the dubiousness of their condition was of a different character. However it posed some of the uncertainty in being hard to feel, and not appearing until it was mediated by the surroundings. Lone was in her early sixties and had had diabetes for ten years. The first time I spoke to her, I introduced the purpose of my study: to get a better grasp of, what it is like to live with diabetes:

> Lone: I am curious as to what you want to know about, right? Because, I think that to have diabetes is such a lonely affair. It really is, right?
>
> Ditte: Yes. In what way is it a lonely affair?
>
> Lone: Well, it is a lonely affair because you have a condition that you cannot feel and other people cannot see you have. So it is always just you. You cannot see in people that they have diabetes, or like; why is she just so tired, or why is she irritable? And you don't sit there and – I mean after all it is also a bit private, right? To have a disease. I will put it like this: recognizing that you have a disease that no one not sees or hears, that is difficult, I think.

In the clinic, knowing and treating the condition was the purpose of the interaction, and measuring the blood sugar was a focal point of that interaction, so the condition was made explicit and observable. Everyday life with diabetes involves other activities and the condition is not observable in the same way. It may come to a point where the condition showed symptoms recognizable to Lone herself, but not to people around her. The invisibility presented a dilemma that many of my informants faced as they moved from and beyond the clinic. In one of our workshops, held in New York, this dilemma was brought up as people discussed how to keep the condition in mind:

> Charlie: I mean, you know, once you are pretty much in check with your diabetes, you do not feel like you have it.
>
> Rosa: Right.
>
> Charlie: Right, you know, and if I eat those cargo Sundays every night, yeah, I am going to be suffering for it, you know, but if I do it once in a while it is not a bad thing.
>
> Rosa: In that case you have to be very careful, because if you are not feeling, well, you have the disease, you know, you get too comfortable, I think you get too comfortable. So you have got to remind yourself that you have this disease and not supposed to eat a lot of ice cream or... For instance, I used to do a lot of baking now I have cut that down. I do not do a lot of baking.
>
> Janet: So it is not just at the start you need this [reminder]?

Steven: Long term,

Charlie: You need a reminder definitely, oh yeah.

Charlie's description of his inability to feel his diabetes resonates with Stephan's depiction of his hearing loss when he was in fairly quiet settings. In both accounts, the medical condition is imperceptible. With hearing loss, problems emerge as disruption of conversations and sometime the hearing impaired person is only aware because other people notice a disruption. With diabetes, there may be no symptoms when the condition is well regulated. It is something that diabetics need to be very careful about, as Rosa pointed out, because feeling well and comfortable might make them forget about the condition and not control their desires.

The capriciousness of the medical conditions initially perplexed me, but also, or maybe for that exact reason, became the crux of my explorations of the conditions as they played out in the everyday lives of my informants. Methodologically it meant that we sought to make our informants help us understand the practicalities of dealing with the medical conditions rather than observing it for ourselves. In the interviews we asked about their observations, and with the diaries, we asked informants to describe situations in which their hearing loss or diabetes emerged as problematic or even just noticeable. Analytically, it steered my curiosity not only towards emergence of the medical conditions, but also to their handling through which they appeared either as problematic or as having been dealt with. It also provided a basis for comparison that may both be hard to feel, but also differ substantially in the uncertainties people face, as will be revealed in the following sections.

ENACTMENTS

The purpose of this chapter is to explore how people with diabetes or hearing loss live with their medical conditions. This reflects the praxiographic attendance to practices; diseases come to be as they are enacted on particular occasions (Mol 2002).

In 'Embodied action, Enacted bodies, The example of hypoglycemia', Mol and Law observe that the body is commonly treated as both a subject and an object; it is a 'body-we-are' as we are able to sense it and a 'body-we-have' that can be measured as an object for medicine (2004:15). Then they suggest that we abandon this dichotomy for the 'body-we-do'; the body that emerges from situated practices. From this, diseases are never to be seen as 'hidden *in* the body or beneath the skin', and that their 'ethnographic description consistently attends to the practices in which it is being done' (Mol and Law 2004:5, original emphasis). In their analysis of hypoglycemia, Mol and Law show that the condition is not simply a matter of low blood sugar values, as described in a textbook. It is articulated on multiple occasions; it is measured (in numbers), felt (as trembling or sweating), produced (as a consequence of treating diabetes), avoided (by constant food intake), countered (by eating when blood sugar drops), excorporated (when the hypo is recognized by a family member because of a change in mood) and incorporated (as an apple is eaten and elevates the blood sugar). Hypoglycemia is done, according to Mol and Law, in all these enactments, not as matters of either knowing the body objectively or experiencing it subjectively, but of as a matter of *doing*. As a methodological implication of foregrounding the practicalities of 'doing' diseases, Mol suggests we listen to people as their own ethnographers, not by attending to their 'perspectives', but as '[people who tell] how living with an impaired body is *done* in practice' (2002:15, author's emphasis). The approach involves attending to practicalities and materialities rather than to subjective perspectives, interpretations and illness narratives. The praxiographic strategy allows me to explore the emergence of hearing loss and diabetes as they are dealt with on particular occasions. A methodological consequence of examining how diseases are locally enacted is that I treat the accounts people told me in a 'realist mode' as 'reports on events' about their medical conditions (Mol 2002:15, 20).

Relational hearing impairment

Inviting people to be their own ethnographers provided me with rich descriptions of how hearing impairment emerged as disruptions of the continuous flow of activities and communications in everyday life. Like Stephan and Karsten, most informants told me that they were not always sure that they heard what was being said, but were doing their best to fill in the gaps or asking people around them to repeat themselves more frequently, and straining to hear when there was more noise or more people talking. At the same time, many of my informants described their hearing difficulties as something that was not a huge problem. In this part, I will describe events in which hearing loss emerged and was dealt with in everyday life.

Other researchers have studied people's ways of coming to terms with hearing loss. In 'A qualitative study of strategies for managing hearing impairment' (1991), Hallberg and Carlsson examine hearing-impaired people's perceptions of the encounter with hearing people. They describe hearing impairment in terms of 'restriction in social interaction'. From interviews with hearing-impaired people, they compose a list of codes for people's perceptions, including 'perception of restriction' and 'feeling of being left out' (ibid:204). They also list the strategies people apply for accommodating or minimizing the impact of their impairment, including strategies for 'controlling the environment' (by instructing others or reconstructing) and 'verbal and non-verbal communication strategies' (ibid:205). While I came across practices that might be coded in these terms, my concern is not to add to these lists. I am not concerned with mapping and coding the repertoire of hearing-impaired people's perceptions, emotion and strategies. Rather than transforming their accounts into categories of emotions and actions, I attend to the local emergence of problematic situations and how they are dealt with under particular circumstances and their consequences.

Disruptions of everyday life

Most of the events people told me about were situations, when hearing loss emerged because it disrupted the flow of a conversation or some other activity. When I asked Karsten to describe how he noticed his hearing loss, he replied that he sometimes drove without realizing that his turn signal was on:

> I got a new car, and that indicator makes a very soft sound. When I make a softer turn, it does not go off automatically, and it keeps on, and I do not hear it, and that is irritating, and my wife can hear it, and that is doubly irritating (*laughs*). Because particularly, when I forget to put it on, she can hear that -- so that is a clear sign of things getting worse.

The hearing impairment became apparent because Karsten's wife pointed out that he did not hear the ticking of the turn signal. The practical and potentially dangerous consequence of having the indicator on emerged as a result of Karsten's hearing being inferior to the level presumed by the technology in his car. Karsten also mention that he and his wife were irritated by the hearing loss, but us for now we will follow Mol's recommendation, keeping the 'realist mode' and concentrating on the practicalities of the event, not to the emotions (Mol 2002). In these terms, his account was about a sound he did not react to, which his wife observed and commented on; it emerged from relations to a technology design and another person. Another research participant commented on this relational character of hearing in the following terms: 'when I am alone, I hear fine'. He could work on his computer with no problems. In terms of the praxiographic approach the disease came into being with the practice of handling the problematic situation, but disappeared when the hearing-impaired person was alone (2002:5).

Hearing impairment thus emerges when it interfered with everyday tasks. Carmen is a 65-year-old woman living in Manhattan. She explained how the construction work on the subway made it difficult for her to get the right train. Changes in schedules, tracks and even routes were announced only over loudspeakers. Most of the time, it was impossible for her to hear what was being said, and she had to ask other people to make sure she got on the right train. As a result, she had developed the habit of looking around for someone who seemed to be paying attention to the announcement (many people do not, she told me) and then ask that person. The hearing loss was thus enacted by waiting, looking and asking for advice.

In both cases, hearing loss emerged in relations among technologies, people, spaces and practical activities. In that regard, it resembles the interaction in the clinic. A crucial difference, however, is that in the clinical setting, the purpose of the interaction is to use designated technology to learn about the hearing loss. In everyday life people orient to other practical concerns, like negotiating traffic and arriving at a destination, and the enactment of hearing loss interferes with these tasks, disrupting the flow of everyday life.

Relating to other people's abilities

When hearing difficulties surface more and more often, some people begin to compare their abilities to their earlier and to other people's capacities. For Agnes, a retiree living with her husband, the volume of the TV became a litmus test for her hearing:

> I turn up the TV when I am alone. I am constantly saying to myself: 'I used to be able to hear it on volume 8. Oh, it is probably just this movie that is a bad production, so I need to turn it up to 12'. Actually, it is interesting, I do not think I even noticed the volume before – I would have just turned on the TV and then that would be it, I would not have any idea about the number. But you start to make connections. It is like putting your thong into a tooth that hurts – oh, it still does, you know, you investigate it. [...] I sometimes visit my grandchildren, and I will say, all outraged: Should Elias not be allowed to hearing the cartoons? He cannot hear that! And my daughter goes 'Mom, why don't you get it? The boy hears fine'. It is hard for me to understand that other people do not need a higher volume.

Hearing does not only relate to the situation in terms of volume, distances and noise, but also to other people's capacities to hear. It was customary for my informants to have first been made aware of their hearing difficulties by their spouse or children. In this sense, hearing loss may emerge as a matter of hearing less well than other people, rather than a sense of not hearing. Agnes was dealing with the discrepancy between what appeared normal to her, and what appeared normal to her daughter and grandson. Realizing that she could not trust her own sense of what was normal, or even explain it away as the result of poorly produced television programs, she used the volume as a standard outside her body as a way of assessing her hearing.

Based on these descriptions of practices and events, we may understand hearing impairment as a consequence of the movement from being alone to being with others who make the discrepancy obvious. Social contexts, however, are not stable and what in one context appears to be hearing loss might not in another. I met Lenard in New York. He is a construction manager, and for many years he had been working on building sites with other men who had also been working around loud machinery for years. He had recently changed jobs, which meant a change in his capacity to hear his colleagues:

> I was just hired with a company and it was important for me to be completely present in the meeting. And one of the people in the meeting was a soft tone, you know, and the space was a large cavernous space, and I just did not follow the meeting very well. You know, I was new to this project, and so it was a very, it was a high demand for me to be really engaged in it. But I was like going, 'wow', you know, I am missing a lot of this meeting [...] And, you know, it's, my past work experiences, I am with working men, who have hearing problems themselves, so it's not, you know, there is a lot of high talk- loud talking things happening, and this context, it's more management people, and, you know, I wanna be equal in being there in that context, and my need to live is depending on my hearing now (*laughs*)

Lenard’s hearing loss was not only a matter of being alone or being with others, but emerged relationally from the change of work sites; it was a consequence of things interacting: the office space and soft voices combined with an increased necessity to take part, to engage and be present, which made for a different kind of enactment of his hearing. This hearing impairment is of another character than the one enacted in the clinic. It is not only a sensory problem emerging as the ear’s ability to hear certain tones at certain sound levels and by introspection. It is enacted in a social and material space, where hearing impairment is in relation to other people’s behavior and capacities to hear.

Subtle changes

The change of worksites made for an obvious and sudden change in Lenard’s impairment. Most of my other informants described something much more subtle. Like Karsten who observed that the social space he could move within might get smaller while he barely noticed it, many of my informants described a gradual and fine change in their capacities. The metaphor of a diminishing ‘radius’ around the body within which one can interact with others, describes the situation of many of my informants. As a consequence, some of them would react by moving to cover the same interactional ‘area’ as before. Ole, a retiree who lives outside Copenhagen and likes to attend open courses at the university, explains how he lives with his hearing loss: ‘Even when I am at the university, I have no problem hearing what he says, because I sit in the front row and not in the back of the auditorium, and I do that, and then I have no problem.’ By placing his body where he can hear the lecturer, he could attend the course without problems. His impairment was not only a result of his situation, but also how he altered that situation, by dealing with his hearing loss. Enactments of hearing impairment are not only a matter of knowing it but intervening and working around it. Ole compensated for his hearing impairment and made it non-problematic, which made him question if he even had a hearing loss.

In her study of people living with acquired hearing loss, Engelund argues that these people gradually recognize their impairment, not only as a question of acceptance, but in a process of conceptualizing fallible communication and moments of personal and relational tribulation as matters of hearing loss (2002). When problems first appear, people do not immediately see them in terms of hearing loss; only slowly and through repeated disruptions does the impairment emerge. Engelund therefore suggests that we describe hearing impairment as 'emergent according with the way it shows to people living with it, and not as 'acquired' as is often done in the field of audiology (ibid.).

Compensating for and pre-empting hearing impairment

While my informants' hearing impairment developed over time, so did the awareness of which situations would cause problems, and how one might compensate for the impairment by bringing the talking person within one's 'radius' of interaction. Stephan, who was quite explicit about not wanting to appear to be hard of hearing, actively engaged in compensate for these situations:

> I am aware [of my hearing impairment], and I am always trying to compensate [...] If am not certain whether someone spoke to me, I get up and see that person. You gotta lean over, you gotta so, you know. I do not know, I guess you're always battling against it, make sure it is not leaving you stranded somehow.

While the sole activity of sitting close to the speaker in an auditorium reflected the subtle increase of impairment and an in situ compensate for the hearing problem, the continuity of such events amounted to something much more dramatic, a matter of ' always battling', or the alternative of being left 'stranded'. It was a demanding fight that involved being attentive, moving around and getting into the right position. Compensating for hearing impairment in this regard is a skill, acquired over time, affecting not only the relation between oneself, the body and movements in a physical space, but also relationships with others. As Stephan described:

> We have very friendly relations with the store on the corner, a woman and her husband. I will come in and she will say '[name of his wife and son] were in, don't buy bread, they already bought bread'. But I am friendly with her husband, and it used to be that he would yell 'hello' from the back. Now I go back there, because I won't really know what he says. He may well have said, 'Stephan did you have a good day?' or something, I just know he said something to me.

Stephan compensates for his hearing impairment by changing the way he interacts with others; he moves closer and initiates a conversation; before his friend might have been shouting something indistinguishable at him from a distance. Even though he may be able to keep his hearing impairment from causing disruptions, it does not vanish; it transforms into being constantly attentive, trying to predict inabilities to hear and change how he relates to his friend.

The process of learning what situations cause difficulties and how they may be dealt with is a matter of becoming skilled in navigating one's social space so that the impairment causes a minimum of disruptions. Some of the events that Stephan observed in his diary and told me about in our conversations, revealed that compensating eventually became too difficult. He described being at a cocktail party:

> Everybody else can hear what everybody else is saying, and I can't, so... I get bored, you get bored, you know, it's looking at the paintings, looking at the people, and then you realize you are not hearing anything that is being said, so it gets boring. And as a result of which, I have always tended to try to push my wife more towards two or three couples.

In some situations he could not break what he heard up into sounds, as he said, and was not able to compensate, so he withdrew from conversations. It was no longer a matter of finding a way in the social space to be able to interact, but to avoid particular spaces and situations in favor of smaller gatherings where conversations were easier to follow. The practice of moment-to-moment adjustments of his physical position was combined with a preemption of the impairment by changing his social habits. Even if he thus developed ways to compensate for his hearing impairment, these made other grave disruptions in his social life – which is a point to which I will return.

Relating to self and others

Not all my informants were as active as Stephan in compensating for and pre-empting disruptions. For Lenard, it was not problematic enough for his to avoid conversations at home. When his wife told me that there seemed to be fewer conversations in the home, I asked if he felt the same. He responded: 'I am not a natural conversationalist in that regard. And if that is because I am a man, or because I come from the country, or ... I am a quiet person in general, so I do not feel I am missing that.' Insofar as hearing emerged in relation to other people, it also emerges in relation to a self. Lenard described his wife as talkative, and tried to converse from the other end of the apartment, whereas he was more thoughtful and quiet and preferred face-to-face conversations. What he found problematic was going to noisy restaurants, where the noise kept him from hearing conversations with his companions: 'What I am missing is other people's conversations, so my coping mechanism is, it is a drag, so I will just daydream, or you know I have a lot of projects in progress, so I will start thinking about those.' His impairment emerged as a practical, yet very subtle difference between listening to other people's conversations, or withdrawing into his own thought space. His wife, though, noticed, he told me, and tried to keep him in on the conversation by acting as his 'hearing aid'; she explained what a conversation was about, when he appeared to be lost. Brooks and colleagues have described this repairing work performed by significant others as ‘intermediating’ between the impaired and their surroundings, and observe that such translations change the situation with consequences for all involved in the conversation (Brooks et al. 2001). Other ways for spouses to deal with the impairment have been observed by Morgan-Jones. Based on her own experience and on research in the field, she describes how a husband or wife may act as a ‘buffer’, a ‘mediator’ or an ‘editor’ of his or her spouse’s talk (Donaldson et al. 2004:35-36). Mol and Law use the term ‘excorporation’ for describing other people’s recognition of and reaction to the disease in such subtle ways. In terms of praxiography, the impairment was not located only in Lenard’s own practical engagement, but also in that of his wife, as she read from his behavior that he could not hear something and then intervened.

In the professional context, hearing impairment combined measurable loss of audibility with an individual’s perception of how bothersome the loss appeared, directed towards the purpose of evaluating a medical condition. In the family context, hearing impairment usually became noticeable through disruptions of everyday life and the practical engagement of dealing with these. In the field of audiology, many researchers have inquired into the social and emotional consequences of hearing impairment and observed that untreated hearing loss may cause ‘smaller social networks’, ‘feelings of loneliness’ (Kramer et al. 2002), depression, insecurity and anxiety for the person with the impairment (Anderson and Green 1995) and frustrations for their partners (Donaldson et al. 2004). These studies attend to psychological and social responses to a physical impairment, whereas I listened to people’s stories as descriptions of a changeable phenomenon, inseparable from a myriad of practical purposes of everyday life. From there, I observe that hearing impairment is relational. It changes with the circumstances in which people find themselves, and only sometimes do the space, sounds and the body’s position disrupt some course of events or interactions that would normally proceed without problem. When alone, people might not have hearing loss, and with others it might only emerge when others make them aware of the impairment by repairing the conversation. Hearing problems are also relational to other people’s abilities, so in a context where everybody heard equally poorly it made another kind of normality, and no one was impaired, but everyone spoke louder. The impairment changed and was changed by the situation, relations to others and to oneself; it emerged as relational impairment.

Capriciousness of diabetes and productions of ‘control’

At a first glance it may appear that hearing impairment and diabetes are essentially different. Where hearing loss emerges situationally since it is a functional impairment that produces observable disruptions, diabetes is a permanent disease of the pancreas and poses a risk of potentially severe complications. In other words, hearing loss may appear to be relational because it interferes with social interaction, whereas diabetes is hidden. However, sticking to the praxiographic approach, Mol instructs us otherwise: never to search for a disease beneath the skin, but only in the practicalities of dealing with it. Ontologically, hearing loss and diabetes are of the same kind; the medical conditions are produced in and through the practices of handling them. Consequentially, attending to the practicalities of dealing with the problematic situations the medical conditions, diabetes too emerge relationally. People with diabetes rarely had instantaneous disruptions, but more often the dubiousness of a condition that is difficult to feel and observe, as Lone puts it, yet poses a potential danger.

How numbers and measurements are used

One of the first practices that caught my attention was the measuring of blood sugar levels. Over the past decades, inexpensive, portable measuring devices have become available for home use, and biomedical measuring is no longer restricted to the clinic or laboratory. In terms of inquiring into and handling the conditions, this appeared to be a very tangible practice and a continuation of what went on in the clinic. In a study of older Danes diagnosed with high blood pressure, Oxlund observes that in preventive health care, 'measurement has become part and parcel of the ways in which people relate to their own bodies' (2012:53). However, from my fieldwork I soon learned that measuring practices in the home was not only a matter of 'living by numbers' (Oxlund 2012). Measuring devices did more than measure (Mol 2000).

When I visited Charlie in his home, he told me how he used the meter to ascertain the effect of a particular food item on his blood sugar, much as Dr. Mogens taught his patients to do:

> [Asked when he measures] If I ate a lot of something I should not - let me see how it affected me, and I will do it for that reason. Like instant oatmeal will make my sugar go through the roof, yeah, but steel-cut oats does not, it keeps it lower. It is hit or miss sometimes, you want to know what food will do that to you - this is what I think is the real reason for that meter. If I am eating something different, then I will know if I can continue to eat it, then I will test.

As our interview proceeded, however, he told me that he did not often measure the effect of what he ate any more. His blood sugar was in control, he said, and he saw no need to go around and test all the time. He mainly measured as a way of preparing for visits to his doctor:

> Usually when I get closer to the visit to my doc I actually do an excel spread sheet [...] I give him the date and time and the food that I ate that day, and then my testing, and then I can just do the average [...] I will measure when I get up in the morning, when I get to work, two hours after breakfast. I take it to one extreme and do it a lot more than I should, you know, like I give him a whole range.

Charlie shows us his blood measuring kit. He is holding the disposable needles that are fitted to the pen to the right before pricking the finger.

Even though he knew his numbers, he did not always know what they meant. He told me that his sugar often was high in the morning, which seemed odd to him, since it had been many hours since his last meal. He did not relate to his body by way of these numbers (Oxlund 2012), but depended on his doctor's reading of the numbers to make sense of them. With time, his practice of measuring had transformed from knowing the effect of specific foods to a matter of knowing that however he translated the doctor's recommendations was okay:

> It [diabetes] changes the way you look at the menu, you know, I will look more to make sure, that I am not getting something that will be all carbs. I will have a burger and fries, but then I will have a tuna fish sandwich the next day. Or there is a salad place... You know, I will break it up. I go to the doctor every 4 months, and he tells me my numbers are good, and as long as they are, you can continue doing what you're doing [...] Before, I would go to McDonalds to get dinner. I would cook, but for the most time it was fast food, take out or something. You know then you got to start thinking, I have got to eat salads. Okay, salads get boring, so you have got to put things in it, you know. Then I got a salad kick and for two weeks I would have salads, and then I am like, no, I do not want more salads. It was not easy to figure out what to eat. There is a lot of material out there. That will help you. You know, I was reading to the point where I was getting headaches. And a lot of it, some of it I found confusing, because you should not have sugars, you should not have carbs. But then you look in this cook book for diabetes and it tells you all these things you can eat, and I am like: How can I eat these things, if I am not supposed to have it? I think after a while you learn it is just a question of moderation. I was used to leave the table and feeling stuffed. I was overeating, now I am like, I do not do that. It is portion control. It is not just what you eat, it is how much.

Knowing how to treat his diabetes had not been easy. He had to translate the dietary recommendations into something he could manage within the practical constraints of a workday.

Advice was abundant and at times contradictory. The number brought simplicity to complexity. Charlie treated the numbers as a measure of his practice of 'breaking down' and varying his eating, not only a measure of the body. While the work involved in measuring, registering and making detailed spread sheets transform features of the body into an *object* for medicine, it also enabled him to a *subject* in control of his diabetes. In a study of Danes with type 2 diabetes, Danholt argues that in some cases, measurements of blood sugar values constitute the premise for a patient to 'become a person in control of his condition, and thus live up to the understanding of the 'autonomous' subject in control of his life'(Danholt 2008:134). It resembles Cussins' argument that clinical investigation and the objectifications that follows with it do not necessarily cause alienation and passivity, but is a requirement for the patient to gain agency in her attempt to conceive (1998). For Charlie, the objectification and the numbers were a resource for assessing his ability to translate and follow treatment advice; it allowed him to produce diabetes in control.

When the number becomes a measure of how well a patient translates and follows treatment recommendations, the measurements allow the patient to set a goal, and navigate the complex terrain of possible treatments of diabetes. Steen was a man I met in Denmark, who had lived with diabetes for seven years. He used his numbers to guide the way that he handled the diabetes:

> I am very focused on goals that I can aim for in my treatment, whether that be the long term blood sugar or some of the other features that are measured like fat and triglycerides and whatever it is called. It is important to me in order to keep a focus, so within a three months period I have some measures I can aim for.

For Steen, the numbers not only helped him to make dietary choices, but also diminished the time horizon of treatment. Since he had a chronic disease that might cause complications in the long term, the quarterly measurements made tangible short-term goals possible. Both for Charlie and Steen the numbers set a treatment goal and transformed the endless possibilities of treating diabetes and live healthily to one single way of knowing their efforts: if the number is okay. In a study of people with risk of type 2 diabetes and cardiovascular disease, Andersen and Whyte argue that 'formative processes' constituted by measuring are about subjectivity (2014). This is done not in the negative sense though, where people are made subject to their risk condition and made sick through measurements, but in the positive sense in which people can reflect and act on their health condition (ibid:274). Numbers thus become associated with personal responsibility and morality; the improvement of health becomes an imperative and knowledge of numbers allows for motivation (ibid.).

As a means to knowing that what a patient does is good enough, the numbers also raise the possibility of disappointment. Jette confided to me that sometimes she went a long time without checking her numbers, because:

> To keep on being confronted with those numbers that just went up and down, I could not handle that [...] if they are good, then I am happy, but if I have eaten healthily and they are high anyhow, I get sad and think: what did I do wrong? Because I really think that I have done as I ought to do.

Jette's way of assessing her own efforts as 'eating healthily' was incompatible with using the meter. Her assessment of her efforts of treating her diabetes did not match the measure of the meter. She interpreted the number as judgment of her interpretation of healthy living, concluding she had done it 'wrong'. As a consequence, she avoided measuring, sometimes for week or months, so that she would not be presented with unexpected results. As she was not able to control the numbers, the practice of measuring did not constitute ability to act upon her diabetes. In a study of people living with diabetes, Simon Cohn observes that many people feel unable to control the interactions of diet, exercise and medication: 'it is not so much being out of control, as being forever vulnerable to unexpected factors' (Cohn 2000:220). The image of risk prevention is associated with individual control and freedom, according to Cohn. It does, however, ignore that people live in complex and unpredictable worlds (ibid: 221).

A few of my informants described unsuccessful attempts to control their diabetes. Rosa, who lives in Brooklyn, is disabled from a failed surgery 16 years earlier, and has had diabetes for about 15 years. Recalling the day she received her diagnosis, she explained to me:

> My doctor tested me and told me I was pre-diabetic […] At that time, maybe I should really have paid attention and tried to get it under control. He said I could control it by what I ate, but I did not. And I became diabetic. I was not accepting it at all. […] I was a very hard worker, and I worked hard -- but I got diabetes after I slowed down, after the surgery, and I had really kind of given up on life. What I had been through was so horrible, and I was not doing what I was supposed to do. But I am still fighting.

In her account, the lack of control was the reason why she deteriorated from potential to actual diabetes. She blamed her bad luck, physical impairment and depression. She explained that she now did all she could to keep her diabetes in control, by taking her medication, moderating her eating and measuring her blood sugar every morning when she woke up. The measuring was demanding. 'You have to have a lot of patience', she explained, as she showed the little book where she wrote down her measurements. Like most people who are not insulin dependent, she made no adjustments in her medication on her own, but regularly saw her doctor who looked at it, and measured her long-term blood sugar before making changes to her medicine. At first it struck me as counterintuitive to put so much work into the demanding and painful measuring, when the results did not seem to have much impact. The practice of measuring, however, did more than produce numbers in a booklet. It was part of her diabetes-control regimen, and in taking the measurements, she was doing the part of the 'control' that she had not done when she was pre-diabetic. As she stated in the workshop, one of the dangers of diabetes is when getting too complacent so her practice of measuring was a way of handling the dubiousness of the condition. In various ways measurements and numbers were her way of taking control of a capricious disease.

The un-enacted diabetes

Sometimes it was hard for me to see how the diabetes was enacted. When diabetes is well regulated it, it might go unnoticed and appear to be a 'shadow disease' (Wittrup in Andersen and Steffen 2013:129). Connie, had had diabetes for six years. She worked in a pharmacy, where she filled prescriptions. For this reason, she was quite knowledgeable not only about medicine, but also about diseases. Diabetes had always been of interest to her, so whenever there was a diabetes-related evening event in the pharmacy, she attended. In one such meeting, the members of the pharmacy staff tested their blood sugars. Connie found out hers was high, and went to see her doctor who diagnosed her with diabetes. When I met her, she was struggling to keep her diabetes in control; she was overweight and had recently progressed to GLP1 (injectable antidiabetics). When I had introduced our research project to her, our exchange proceeded as follows:

> Connie: I am a very bad patient [*she laughs*).
>
> Ditte: Why is that?
>
> Connie: I am not very good at accepting my diabetes -- and continue to live as did before, and that is not very good.
>
> Ditte: Does your doctor say that or who..?
>
> Connie: No my doctor says my blood sugar is okay, but I am a bit overweight [she laughs]. It would be very good for me to lose some weight, but I do not do that […] I saw a dietician, I met with her once a month, and she was a very nice person. I am not good at keeping a diet, so she gave up. I have to lose – it is in my mind I have to make the change. It is very, very difficult –

She talked about how she had initially been very careful in the first few months after the diagnosis, but then fell back into her old habits. She told me that she needed to lose weight, and even if she bought low fat meat, when she went shopping, she told me, she would end preparing gravy with cream when she was in her kitchen. During our conversation she had white bread for breakfast, and said she liked it so much, she could not give it up, though she knew she ought to. The prescriptions about healthy living that she knew so well, seemed far from her everyday life:

> I did not feel any change, and I still do not – I have never had a low blood sugar, and do not know how it feels, and I do not feel if it is high – I do not feel the difference, that is maybe one reason why it is hard to keep a diet, I do not notice any change.

In practical terms, it might seem that her diabetes was enacted in her morning and evening routines of taking medication. The point I want to make here is the importance of seeing the enacting of a disease not only as a matter of performing a skilled practice, but also in the struggle to adopt a different one. Where most of the hearing-impaired people I met found ways of repairing some of the disruptions their impairment caused, diabetics like Connie were struggling to make a difference that mattered.

Colonization and transformations of everyday live

Another way of doing diabetes at home was by transforming the framework of being a patient in need of treatment and control into something else, so that everyday life was not about being a patient and it was about gaining control. I met Mona in Denmark. She was still recovering from left side paralyzed from a stroke a few years earlier. She described hiding her crutches and not wanting assistive devices in her home that made her think of herself as a patient:

> I am maybe a little crazy, but I do not want to have the pills on my table, because it reminds me that I am a patient, and I do not want to be a patient. I do not want to have it remind me that I am weak, so everything is put into boxes, so it does not remind me – that is very important for me.

By hiding medications she was transforming diabetes from a disease with a strong moral imperative about how she ought to live into something that should not dominate her life. When my colleague and I visited Mona in her home she had set the table with cakes, but with only two plates instead of three. She both brought about the temptation of having cakes, and resisted it, as a way of being in control of her desire (see also Danholt 2008). As we talked about how she knew what to eat, she told us how she had been introduced to lifestyle change in a way she found unbearable. A dietician presented her with a plate divided into thirds:

> It shows a plate with some meat, vegetables and potatoes. And I nearly – I do not eat potatoes, and I really like fresh green salad – but boiled vegetables? I thought, I'll die if I have to eat that. After a while I found out how to make a stew without butter and all that. I had to make my own experience about how to make the food, and that was the hardest in the beginning; no sugar and no fat – how can you make any food without that, I was thinking. But I discovered that it was possible.

The dietician's picture of food translated eating into a matter of obtaining specific nutritional components; into a matter of treatment. Mona herself made a different movement. Cooking had become her passion; she showed us her stash of cookbooks, homemade marinades, healthy oils, spices and vegetables. She explained how she discovered new flavors and experimenting with recipes. By preparing healthy food, she was enacting not-being a patient while treating her diabetes.

With the concept of ‘chronic homework’, Grøn and colleagues suggest that chronically ill people and their families often are subject to extensive expectations about ‘home care’ or ‘self-care’ as part of their treatment (2008:72). They ask if ‘chronic homework’ points to an expert-driven colonization of everyday life (ibid:91f). Mona’s practical transformation of the homework assigned by the dietician suggests otherwise; she does not allow the expert to translate her food into unappealing nutritional components.

Like Mona, Leif transformed diabetes into a practice that kept him from thinking of himself as a patient. He lived outside of Copenhagen with his wife, and had had diabetes for ten years. Around the time of his diagnosis he was very busy working as a consultant, slept very little and ate unhealthily. He had since changed jobs and has been running for five years. He had run several marathons and was training regularly in a running club. By the entrance to his house was a white board with his and his wife’s personal records and goals for the year. Leif described his running goals as his *own numbers*, and said that his blood sugar numbers were for his doctor. He had transformed the ‘chronic homework’ to his own fight to run faster, break his personal records (marked ‘PR’ on the board) and reach new goals. When I visited him in his home on a Friday morning he was preparing a large breakfast with eggs, bacon, bread and pastry. Unlike Mona, he did not enact being in control. He ate a large portion, because he was a runner:

> Leif: I do not have any particular dietary considerations. There are no food items that I do not allow myself to eat because I have type two. However, there are some I do not eat because I would gain weight, but there is probably a reasonable relation between what is healthy in one regard and the other. But the reason for eating more healthily has changed. First it was because of diabetes, but now I do it to lose weight. It is the same thing I do, but the grounds and my thoughts about it have changed.
>
> Ditte: Has that changed your commitment?
>
> Leif: It has become easier, because somehow I do it more for my own sake, so that I will be able to run a certain distance within a given time, for me that is a better reason than a doctor telling me I have to do it. I am competitive, I am not running on elite level, but I want to measure myself.

By running he not only lost weight, but also transformed himself from a patient needing to comply with his doctor’s instructions, into an athlete striving to reach his goals. In translating the issue of diabetes to something else, he created a space in which he could compete with himself and win. The transformation changed him from striving to take control and avoid getting worse, to a situation in which he already was in control and working to get better. Unlike Mona, who set up a temptation and resisted it, Leif created circumstances that allowed him to indulge in a hearty

In the hall, Leif had a whiteboard with his personal records as well as his goals for running different distances. He said these were his *own* measures; the blood sugar values were for his doctor.

breakfast. Mona used her culinary skills to allow herself to hide her pills so that she would not have reminders of being a patient. In different ways, Leif and Mona constructed diabetes to keep everyday life from being colonized by 'chronic homework'.

Unexpected changes

Diabetes however, is not only a condition that a person can transform and *act upon* as an active and engaged subject. It may also unexpectedly *act upon that person* (Whyte 2002:172,176). I meet Claus through a training centre where he attended a course in living with diabetes. He was one of the few people, I met, who had been diagnosed with diabetes because of a complication. He told me that he had noticed a pins-and-needles sensation in his feet, as if they were asleep. His doctor diagnosed him with diabetes, and told him that as a result, he had neuropathy: damage to the nerve endings in his feet. With the diagnosis, the pins-and-needles sensation was translated into an irreversible complication of diabetes. Claus told me that he had treated the neuropathy with medication for a few months, but stopped because he was concerned about the side effects. In the meantime his blood sugar level had been brought into a normal range, but his feet were still constantly cold and felt as if they were asleep. 'It is two separate things', he told me, 'the diabetes and the feet'. The complication of neuropathy, which was irreversible, became a separate issue from the diabetes.

Steven was a person I met in New York. He was in his early sixties and had been diagnosed ten years earlier. He was retired and living with his family near the beach. When his diabetes showed complications because of a minor accident where he fell and hit his knee, it was a wakeup call for him:

Steven:	Thank God, I got a shot at it. Before that, I was thinking it was gonna be a much shorter life [that] I was gonna die young. I mean I am only 62, but I did not think I'd make it past 70, the way that I was going...
Ditte:	You did not think so?
Steven:	No. I, I could not stop it, it is an addiction to sugar. I could not stop it. And then with this accident I have stopped, and I think that I will live a lot longer than 70. I want to see my daughter get married

According to Steven, diabetes was done in different ways over time. Before his accident, he had not paid much attention to it. Diabets did not take up much time in his life, it was not visible to him and he only occasionally took his medication. The accident was first only a matter of him hitting his knee, but as time passed, the knee swelled and became painful. A month before our interview, he went to see his doctor, and he was hospitalized for four days. He had an operation; intravenous antibiotics cured the infection in his knee. He was told that the infection has been serious because of his poorly regulated diabetes. As he showed us around the house, he used a cane because his leg was still healing. He said that since the accident he had started being more careful about what he ate and was taking all his medication. He demonstrated his modesty with a half-eaten sandwich in the fridge and shared his low-fat snacks with us. Diabetes may unexpectedly result in complications, some of which may encourage further control. Other complications are irreversible and may present other problems such as having to live with numb, cold feet.

In the clinical setting, the embodied measuring of blood sugar levels played an important part in the production of diabetes. The patient's living with the condition was related to the numbers. Moving and eating were transformed into lifestyle activities that needed to be inquired into and learned anew so they could be adjusted to reach the treatment goal. In the home, diabetes was 'done' in a myriad of ways. What at first appeared as a continued practice of measuring and knowing blood sugars was an attainment that was transformed in the home and directed at different objectives. The numbers did not only evaluate the patient's lifestyle and compliance with medical treatment. For some people it formed the premise for simplifying complicated treatment recommendations; for others it created a possibility of producing a 'controlled' condition. For still others, the presence of numbers not accompanied by any symptoms or signs, meant that the condition remained vague and distant. In some cases people took it upon themselves to transform the requirement of 'chronic homework' into their own passionate projects of training for marathons or learning to cook in a new way. Diabetes however, is not only a condition that may be controlled, left to itself or transformed; it may also cause unexpected changes and complications, in some cases permanent and in other cases taken as a warning about the need for change.

In examining the practical enactments of diabetes and hearing loss as they unfold in everyday lives of people living with them, I have depicted them as matters-in-the-making emerging from situated interactions. I have shown that hearing impairment is a relational condition, emerging in relation to specific situations and other people's abilities to hear, but also altered as it is counteracted or pre-empted by avoiding certain situations. Diabetes too emerged as relational, but in a different way. My informants with diabetes treated measurements not merely as a way of registering blood sugar levels, but also as practices of creating simplicity in the complex treatment of the condition, breaking down the seemingly endless time horizon and establishing a sense of control. As people thus act *upon* their diabetes, it is transformed so that their everyday lives are not colonized by health concerns. However, the condition sometimes resists the attempts of control with consequences that might not be changed.

MAKING CONNECTIONS

As much as the praxiographic approach has allowed me to unfold how medical conditions are practically enacted in everyday activities outside the clinic, it also limits that analysis, as became clear to me when I listened to my informants. Treating accounts as 'events people report on' (Mol 2002:15) steers attention towards practicalities, materialities and events, but seemed to let another kind of practice recede into the background: the practical work that people conduct, as they selectively connect diverse events and relate them to their medical condition. I will illustrate with two examples.

When I visited Carmen in her Manhattan home, we talked about how she would notice that she was hard of hearing. She had completed our auto-ethnography kit, wherein one task consisted of making observations about the problems caused by her hearing impairment. She talked about events where mishearing or misunderstandings occurred, and compared two situations. In the first, she was in a hardware store, and had to ask the sales clerk to repeat himself, but did not associate this with her own impairment:

> There is background noise in the hardware store, so it wouldn't have been unusual for anybody to have to ask him to repeat himself -- and plus he speaks with a Russian accent.
>
> (*Later the same day she had an errand in the bank*)

> I misheard what he [the teller] was saying, so I felt embarrassed. And because he had to say to me: 'No, what I meant was...' it made me feel old, that I was not understanding him clearly. Because it was not a complicated statement, he made, I mean... I didn't feel embarrassed in the hardware store because of the environmental situation, but in the bank, I mean there were no excuses for not having heard what he was saying.

Carmen was talking about events that took place in noisy environments, where mishearing was to be expected and repair of communication were made. However, her account also shows that only some of the disruptive events were attributable to hearing impairment. A misunderstanding is not a matter of impairment per se. There was another skilled practice involved here: knowing when something is 'unusual' and thus related to the condition. While attending a diabetes workshop in New York, Charlie noticed:

> I had time to kill [on my way here], I was walking through Grand Central and came by a Starbucks, and saw the cookies, and I said [to myself], I could use one of these, but then it was funny, I knew where I was going, and I felt guilty. So I was like, all I will have is my latte, that is it.

The event he described was an enactment of diabetes, where spare time and a cookie displaced in the counter of Starbucks produced a situation that, to him, was about guilt. However, Charlie also pointed out that he associated the cookie only with his diabetes, because of what was on his mind at that time.

In her study of arthrosclerosis, Mol argues that taking people's accounts as stories about events is a way of getting what one could have observed by following their daily routine, when the patient 'does what he can and bumps up against what he cannot' (Mol:2002). Had I been following Carmen and Charlie, simply by observing these events, as an outsider I could not have made out what instances of 'not buying a cake' and 'misunderstanding' should and should not have been ascribed to the conditions. In other words, my material is not fully unfolded with the praxiographic focus on enactments, and I need a more inclusive understanding of *practice* that does not only attend to how living with a disease is *done*, but also how these practical events are rendered meaningful. It is this meaning-making work, which I see as part of reality construction, and which is left out in the praxiographic approach[1]. In ethnomethodology, researchers like Mol have suggested treating members of society as their own ethnographers (Pollner and Emerson

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[1] When I attended a master class with Mol in the fall of 2014, she commented on an extract from my thesis and told me that in *The Body Multiple*, she bracketed matters of interpretation and meaning making, because they were dominating the field. In other words, it was a local strategy to make a radical break with the dominating illness-disease distinction. However, she argued, interpretations are part of these practices, and as a collective we need to find ways of combining these practices. With my work on combining the meaning making with the enactment, I hope to make a contribution to this work.

2001:126, Gubrium and Holstein 1997:42ff). From an ethnomethodological stance this does not only entail that we listen to our informants' descriptions and observations, but treat their narratives as reflecting, interpreting and constituting of their social reality (Pollner and Emerson 2001). When Karsten told me about not hearing the turn signal in his car, this event became meaningful, as he interpreted in as 'a clear sign of things getting worse'. He did not simply describe interactions, but also interpreted and connected the event to his understanding of hearing impairment. Dewey says that we live comprehensive lives in a world where things emerge in complex entanglements, and distinctions between external conditions and internal structures, between objects and subjects are analytical devices that allow us to break up and organize the world so we can act in it (1925:18-19). From this stance, events are not meaningful in themselves, and only upon reflective analysis does our world become intelligible. To understand the meaningful constitution of diabetes and hearing loss in everyday life, we must include the practical work of connecting and contextualizing events. As Gubrium and Holstein notice: 'While the act has physical appearance and can be observed, it is not appearance per see, but rather what appears to be that is critical' (1993:655). In other words, foregrounding the enactments of disease in people's account, not only brackets 'perspectives', it also turns attention away from the practice of selecting and interpreting events, so they become observable and meaningful.

Marking medical conditions

From an ethnomethodological concern for such 'interpretive practices' (Gubrium and Holstein 2012), Gubrium has, with different colleagues, described and analyzed mundane practices for constructing and sustaining the meaning of disease categories (Gubrium and Lynott 1987, Gubrium and Holstein 2012, Gubrium et al. 2003). Attention is one of the practical processes, where people meaningfully construct their reality through 'artful, minute and continuous work' (2012:90). In one study, Gubrium and colleagues thus examine how stroke survivors continuously reckon their capacities as they engage in practical contingencies of their everyday lives (2003). They conceptualize this work as an alternate practice of assessment in the progress of recovery. In other words, they displace the mundane understanding of 'assessing' physical functionality from the clinical context to the context of everyday life (ibid.). The authors use the term 'marking' for the meaning-making work of relating the daily experience of bodily functionality to emerging criteria. In this process, stroke survivors contextualize everyday activities in three areas of experience: self-definition, comorbidity and age. They construct meaning of their impairment as they perform their tasks of daily life (ibid:203). By continuously orienting to their condition in terms of such 'markers', the stroke survivors produce a varied assessment of their recovery. In contrast to formal assessment in the clinical context, where particular activities are deemed relevant to recovery prior to the experience of it, this informal assessment develops during the recovery process. 'Markers' are not stable and unchangeable points on a scale, but continuously interpreted and serendipitously learned (ibid:210). It is by relating and connecting everyday events to understandings of self, body and everyday practicalities that survivors construct meaningful assessments. Gubrium and colleagues argue that the reality constructing practice that stroke survivors engage in is not only a matter of observing and dealing with problematic situations, but also the work of marking those events, connecting them to the condition and seeing them in a meaningful context.

From this understanding, we may see Carmen's account about her hearing difficulties as a way of connecting the events she experienced to an understanding of when it is 'normal' to repair a conversation and what it means to be 'old', and thus as reality constructing interpretation. Likewise, Lee linked the lack of conversations in his home to his understanding of himself as 'not a natural conversationalist' as a marker that produced an assessment of his impairment.

When I spoke to Agnes and her husband in their home, she told me, how being with her friends made hearing impairment appear normal: 'Often when we are with our friends of the same age, there is regularly one of us, who has not heard what was said, then we just pause and laugh a little. It is a basic condition in our age group'. For her, growing older with peers meant that hearing difficulties were assessed as a normality rather than abnormality by the marker of the ageing body. Many of my informants had health issues apart from their hearing impairment, and it was not unusual see them as connected. For some people, hearing impairment appeared the least of their health concerns, because they had more severe impairments or had undergone surgery, but that was not always the result of the comparison. When I visited Carmen in her home, I also met her mother, who had Alzheimer and needed around-the-clock caregivers. During our conversations, Carmen's mother was sitting in her wheelchair, and one of her caregivers was feeding her lunch. This did not seem to make Carmen's hearing loss appear less serious. On the contrary, Carmen was concerned that she had difficulties communicating well with her mother's caregivers. She told me that she had seen an audiologist, who had told her that her impairment was not severe enough to need treatment. Her way of handling her impairment, she said, was be to be very forthcoming about her hearing and ask the caregivers to tap her shoulder if she did not hear what they said to her. Unlike Stephan who actively fought his hearing impairment as not to appear as 'an old man', Carmen fought her impairment, but was less concerned about appearing old in her home. Situated in a home equipped with wheelchair and other assistive devices and, surrounded by caregivers, she found herself in a setting where much of the activity was about accommodating disability; it did not seem to bother her that she and her caregiver treated her hearing difficulties as an impairment. Stephan, however, was living with his younger wife and their 11 year old son. He was working with younger people, and was concerned about making up for his hearing loss so that other people would not think of him as old and deaf:

> When you are my age you develop sensitivity about things; in other words, I never told anybody [at work] that I am 60, they are all astonished that I am 60. I would have avoided saying that in an interview. People do not like hiring people my age, and the last thing you want to do is have age-related disabilities in a competitive work environment. So other people may not hear somebody, I am very quick to get up, and say 'let's go see what Andrea said', so there is not some general sense of 'Stephan is old and hard of hearing'. So it is a compensation, not just for the physical and anatomical fact of being hard of hearing, but also the social context you're in. You want your work environment to think that you are as capable as everyone around you, and you getting older, that becomes a sensitive issue. I think, I want to make sure anything like that is not a negative mark against you.

Stephan took hearing difficulties as a sign of being old and disabled, which he wanted to avoid. The condition is not only enacted in the events, but also made meaningful as these events pertain to understandings of self, body and everyday life. In reflective analysis, problems are located with the purpose of solving them.

Likewise, it was the result of a situated analysis, when Charlie related to the cookie in the counter as a temptation and a source of guilt. As I have demonstrated above, the practice of eating unhealthy food was taken in different ways depending on how the situation was experienced. Charlie described it as a matter of breaking things up, so an unhealthy lunch was followed by a healthier one the next day. When I visited people they would relate to their eating by explaining, like Mona, that she could not have cake because of her diabetes, or Leif who told me could have eggs and bacon because he was a runner.

To understand how people live with medical conditions, we must understand their accounts not only in terms of 'events they report on', but also in terms of *how* these events are made meaningful through a situated analysis. I suggest that we see people as their own ethnographers, not only in the sense that they observe (Mol 2002), but also as they, through interpretive work, meaningfully account for their understandings. It may seem that I have gone full circle back to perspectivalism, where patients make sense of their medical condition from a subjective perspective. I do argue, though, that attending to meaning-making as a practical accomplishment, does not take me back to persepectivalism, but to a different notion of practice. Mol's notion of practice, places human and non-human actors in a symmetrical relationship, both appearing in a flat ontological landscape of interactions, where no intending subjects stand behind and no determining structures are above. A phenomenon only *is* when it is enacted, which explicitly 'leaves the actors vague' (2002:33). My informants, however, were not mere actors in an emerging landscape, they were actively making their ways through an uncertain world, in a constant movement among acting, reflecting and being in the world (Dewey). In chapter one, I suggested that we think of Mol's praxiography as an empirical development of Dewey's pragmatism. They both foreground practices to understand our engagement with the world and to overcome what they see as a false dichotomy between epistemology and ontology. However, there is an essential difference; where Dewey sees our engagement in the world as a matter of inquiry and directed action, Mol suggests that we leave meaning and interpretations behind, as they belong to subjective perspectives. In Dewey's pragmatism, humans engage in the world in the mode of 'prehending, reacting to and interacting' with their surroundings (Boisvert 1997:14). The subject-matters they deal with are full of latent possibilities that emerge only as the result of directed inquiry (Boisvert 1997:37). They are not only *acting*, they are also *concerned*, and their inquiries are directed by the objective of locating and solving problematic situations[2]. Dewey therefore attends both to *how* people act, and *what* they strive for (1925:18)[3].

In medical anthropology, Whyte has developed a pragmatic understanding of inquirers engaged in prehending and reacting to their uncertain world (1997:18ff). Using the term 'situated concern', she points to the simultaneous recognition of being faced with uncertainty and the active engagement of undertaking to deal with it (Whyte 2009:213, Whyte 2002:172). Health issues are dubious affairs and matters of uncertainty, she observes, characterized by unpredictability and a lack of absolute knowledge (Whyte 2009:213). This uncertainty may be seen as problematic, but to Whyte, it forms 'the basis of curiosity and exploration; it can call forth considered action to change both the situation and the self' (2009:213). Acting from a situated concern is a matter of actively and intentionally reacting to particular circumstances and uncertainties (2002:175). It is a tinkering activity driven by doubt and hope. With this analytical approach, people are not only actors in enactments of their conditions. They live in situated realities and are concerned about situations that appear problematic and in need of action.

From this position, we may understand hearing loss and diabetes as emerging when people engage with them in light of an objective, whether that is to navigate through traffic safely, being treated the same as their coworkers or to avoid feeling like a patient while treating their diabetes. Their practices of dealing with medical conditions are not confined to enactments, but also include the interpretive practices of associating their hearing impairment or blood sugar values with their practical problems and with meaningful understandings of body, aging, self and others.

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[2] That does not entail that action is driven by a motive inherent in the individual (an argument I elaborate in chapter five). By contrast, I argue that people act as part of a practical project they are engaged in as they undertake to locate and solve what is problematic to them (Dewey).

[3] This mutual attention to the *how* and *what* is also found in the work of Gurbrium and Holstein, though in a slightly different sense. They argue that we need to consider not only *how* the everyday interactional work of reality construction is performed, but also *what* situated realities people are located in: 'what everyone concerned is up against (or has with them)' in constructing reality (2012).

Considering hearing loss and diabetes as matters of 'situated concerns' includes both the practical doings of dealing with health care issues, the situated reality of people's lives and the concerns that make a situation appear problematic and in need of remedy.

SOCIAL CIRCUMSTANCES

In handling their situated concerns, people do not act alone: 'the process of questioning, doubting, and trying out is about social relationships as well as individual disorders' (Whyte 1997:3). Any concern is situated within social circumstances and affects relations with other people, and they are rendered meaning full through social interactions. As I observed above, hearing impairment is handled by way of repairing conversations, avoiding disruptions by moving around in space and pre-empting the impairment by changing the circumstances for interacting with others. It is matter of movement and change in a social space. The social circumstances for diabetes care are of a different kind. Even if family members are engaged in the care of diabetes, the disease, unlike the ability to hear, is not altered through interactions. What is most striking about the social circumstances in diabetes is the moral concern for and attempts to *control* the condition. This section is about social circumstances. I explore how people actively engage with one another in a practice of relating; how experiences and interpretations are related to those of other people, and how dealing with the medical condition is a social matter.

Alternate epistemic authorities of hearing

The world changes as we interact with it and through other people's reactions. From my conversations with hearing-impaired people and their spouses, it became clear to me that the meaning-making of hearing impairment was part of everyday negotiations and interpretations, and the situated concerns that steered inquiry of the conditions were social matters. In the clinical context, hearing was first and foremost a capacity in the brain, known by sensations that were mediated through technology and by introspection. What made hearing impairment problematic in families was not first and foremost a perceptual matter, but its consequences for interactions. As a consequence the epistemic authority to know ones hearing differed substantially. In a conversation I had with Lenard and his wife Carolyn, she observed:

> Carolyn: I mean all of us are only hearing what we hear, which is a really interesting thing. It is just like memory, you know, in a way. And then, what you make of what you hear, or what you see, really is up to the individual. So, and when I was fine with him not [hearing], because I kind of feel, reality is something that, you know, you're fifty percent creating anyway, in a way, with your own imagination and responses. It

was just when, it was mainly, when he would be upset about something I'd said, when I did not say that. That was when we were like, I was like.. 'Now you're in a bad mood, and you actually are hearing something that I did not even say'. So things like that. Because then you can really see it, the imagination really does work…. I would be like, I did not even say that.

Lenard: And then I would apologize.

Carolyn distinguishes what one perceives from what one does; what is in the mind is not important, she says, but how Lenard reacts as a consequence of his mishearing is of crucial importance. The problematic situation, in which impairment occurs, is not in Lenard not hearing, but in the argument that arises from the misunderstanding. Lenard's epistemic authority to know his own sensation recedes into the background, while his ability to engage moves to the foreground.

It is not a surprising finding that hearing impairment is a social matter. Researchers have previously pointed out that hearing impairment can be frustrating, not only for the impaired, but also for their spouses, who must constantly repeat themselves and endure other communication problems (Donaldson et al. 2004:31). In their literature review of 'the spouse's perspective', Donaldson and colleagues approach impairment as a matter of diverging perspectives, often elicited through interviews or surveys. They observe that spouses 'may experience a range of emotions in relation to their partners' hearing impairment, including loss, confusion, sadness, irritation, anger, frustration and embarrassment' (ibid:31). This approach reflects, attends to the subjective perspective as a particular person's emotional reactions. In this section, I attend to the social circumstances of hearing impairment, not as a matter of its impact on diverging perspectives, but as a site for collaborative meaning-making which is 'social in the sense that it is interpreted in terms of others' related experience' (Gubrium and Lynott 1987: 275). I explore how hearing-impaired people with their spouses transform everyday experiences through a shared, situated analysis. I attend to people's experiences, not as distinct and separate reactions to the impairment, but as meaningful interpretations that develop in relation to other people. It embraces the understanding that the stories we tell each other are rooted in social circumstances, as Dalsgaard notices, 'retelling one's experiences in the presence of others is a way of renegotiating retrospectively one's relation with others' and through a reconstruction of the past people try to change the present (Dalsgaard 2004:53).

When hearing impairment is located in its consequences for social interaction, as it often was amongst the people I met, it reframes the possibility for claiming authority to one's sensations. During one of my conversations with Stephan, he reflected on this aspect of hearing, and the loss of legitimacy to know what he heard:

> It is just, you know, a marriage has a lot of tensions, and if you say, I thought we were gonna have sausages, there is a tendency to say, well, you did not hear what I said. And I have a tendency to say; well yes, I did, and you said, we were gonna have sausages… So there is this kind of -- and I have always believed that the hearing issue was just a red herring thrown into it. While you cannot argue your position, because you cannot legitimately say you heard what she said, when you cannot hear a damn thing […] It is always then a part of a normal back and forth in a marriage as to how legitimate it is. Marriages, I doubt that anyone is very fair in them, you know. So there is that, as I say. If we are having a little dispute as to who misunderstood who, I am a loser in that argument.

The impact of hearing went beyond the single event in which it surfaced as problematic. It changed Stephan's position in his marriage, and what claims he legitimately could make. In other words, his wife treated his impairment as the context for interpreting little tensions and misunderstandings in their marriage, and he could not defend his position, because his hearing was unreliable. We asked Stephan to interview his wife about his hearing impairment. First she explained how he would sometimes not hear what she said, but then she took over the interview and asked him if he could recognize her description:

> Ellen: So did what I described seem to be what you experience?
>
> Stephan: I think you are probably being kind, I think there is a greater frequency of times in which you've said something to me, if I am in the other side of the apartment and I haven't -- I am not even aware that you actually--
>
> Ellen: So I just assume that it's your natural inclination to ignore me.
>
> Stephan: (*Laughs*) Well that's -- that would be causing a problem in our marriage because it's not. I would never ignore you. But there are occasions in which I think 'I know that she said something to me. I wish I could have heard it, but am I gonna get up from my computer and go into the bedroom or something?', and I do think that that's a function of my hearing.
>
> Ellen I see, so you mean all the times when I repeat things, because I repeat things a lot, but I don't think of it as that you did not hear me, I think of it that you weren't paying attention.
>
> Stephan: Right you think I am not paying attention when in fact...
>
> Ellen: …when in fact you are just not hearing.
>
> Stephan: Right, and if I get frustrated some part of me is thinking: 'Well she's on the other side of the apartment facing away from me she knows my hearing isn't great so why doesn't she turn around and speak louder?' And I think what happens with people who have hearing loss is they start getting frustrated at the world as though the world should be making up for their hearing loss.
>
> Ellen: And the world does not even think that you're have a hearing loss, we think you are a perfectly normal ordinary person who can hear exactly what is being said.
>
> Stephan: But is just not paying attention.
>
> Ellen: Right.

As Ellen and Stephan discussed their understandings of Stephan's lack of participation in conversations, they were negotiating an understanding of hearing impairment, but also of responsibilities for handling it. Stephan, on the one hand, argued he had more of an impairment than Ellen realized, and that his unresponsiveness was 'a function' of his hearing, something biological and beyond his control. She, on the other hand, accused him of not paying attention to her. The consequence was a disagreement about who should move closer to the other – if he should get up and come to her, or she should talk to him from a shorter distance. While Carolyn and Lenard's interpretation of his hearing impairment informed their respective understandings of a disagreement, the ambiguity of Stephan's hearing loss created an uncertainty about how to interpret his lack of reactions.

Stephan and Ellen tried to separate the issues of attention and impairment, since they frequently merged. Many of the couples I interviewed talked about how hearing impairment was reinforced by other personal characteristics like absent-mindedness or a tendency to become absorbed in work, both of which make it even harder to maintain the flow of conversations. The entanglement of hearing with other issues and practical and emotional consequences together with the ambiguity of the problem caused not only frustration, but also practical transformation of the condition, as showed in a conversation with Agnes and her husband, both of whom were hard of hearing:

> Erik: I first noticed I had something with my hearing, because of the tinnitus, I mean *that* was the trigger. But then I have succeeded in living with it without feeling bothered by it.
>
> Agnes: Would it be right to say that the bother maybe lies in the responses from your surroundings – as they react to that you do not hear as well as you used to? (*Long pause*) Would you say it does it not bother you when I freak out? I am a little harsh now, right?
>
> Erik: Well, yeah, but that is assuming that my hearing is degraded and I therefore do not hear. But that is not *it*. If for some reason, I have switched off, and I've only heard half of what is being said and not the other half...
>
> Agnes: I just don't think you can…
>
> Erik: So it not outright *hearing*.
>
> Agnes: But you cannot separate it. With the little hearing impairment and a distraction in advance, the hearing impairment is reinforced. That is just how it is. I do not know why. But two plus two is not always four, it is five – well, that is the case here, I think.
>
> Erik: Er-mm
>
> Agnes: I know for sure that what I am talking about here today was not something we were talking about, or had as a consistent problem when we were younger. It simply wasn't.
>
> *A little later in the interview, Erik leaves the room, and Agnes tells me:*

> Agnes: Every day, I have to -- Because Erik might listen, but he does not make a sound, so that I know he hears me. I need to catch his attention by saying: ‘are you with me?’ or ‘are you listening?’, and I think it is condescending, but I have to do it or I will lose a lot of our communication with each other [...] And I can feel that it bothers me, to feel that I am not being listened to – and in fact it is about hearing.

Agnes and Erik engaged in a shared analysis of the causes of disrupted communication, working to set apart hearing difficulties from situations of not listening. While Erik could not claim that he heard all Agnes said, he claimed that he did not experience problems with his hearing. However, Agnes holds that even if he does not experience not hearing, he must be bothered by her reaction. As Agnes observed when I was alone with her, she was changing her way of relating to Erik, so their communication would still flow, but she struggled to change her interpretation of not being heard.

Living with hearing impairment is a continuing matter of definition and interpretation for both the impaired and the spouse (cf. Gubrium and Lynott 1987:283). By attending to the practical construction and transformation of meaning, the impairment emerges as the result of situated inquiries, and not as an impairment seen from diverse ‘perspectives’ of doctors, patients and spouses. In and through practical meaning making, people negotiate their epistemic authorities and discuss responsibility for misunderstanding, repetitions and for moving closer.

Interpretive transformations of diabetes

It was a reoccurring issue amongst my informants with diabetes to balance the role of the condition in their lives. Even if almost all my informants expressed concern about not letting diabetes take over their life, there was no straightforward way of translating the future risk of progression to meaningful actions in the present. It was a matter of transforming and balancing the ‘chronic homework’ assigned by health care professionals. As we brought people with diabetes together in workshops, they often engaged in conversations about how to interpret their present in light of their future risk.

Gubrium and Lynott have studied how the burden of caring for a patient with Alzheimer’s disease evolves in a process of practical definition and interpretive transformation (1987). In support groups, caregivers exchange stories and construct meaning out of their burden. Different images of the burden were raised; one participant associated it with frustration and stress, but another related to it as an opportunity to demonstrate virtue by taking good care of her beloved husband. Gubrium and Lynott point out that caregivers are not easily categorized by either one or the other understanding of the burden, but that the images work as tools for representing and ascribing meaning to their experiences in the ongoing interpretation of the always-changing care process. In the support group, meaning making emerges as an interactional endeavor, where people mirror their own experience in the stories of others.

In the workshops we arranged during our fieldwork, the participants shared their experiences of living with diabetes and brought about different images of how to interpret and balance ‘chronic homework’ in relation to other concerns and their expectations about the future. In one case, we had asked our participants to engage in a task we called ‘the future journey’ and imagine how their life with diabetes might be in the future. In the following Connie and Mona engage in their imageries:

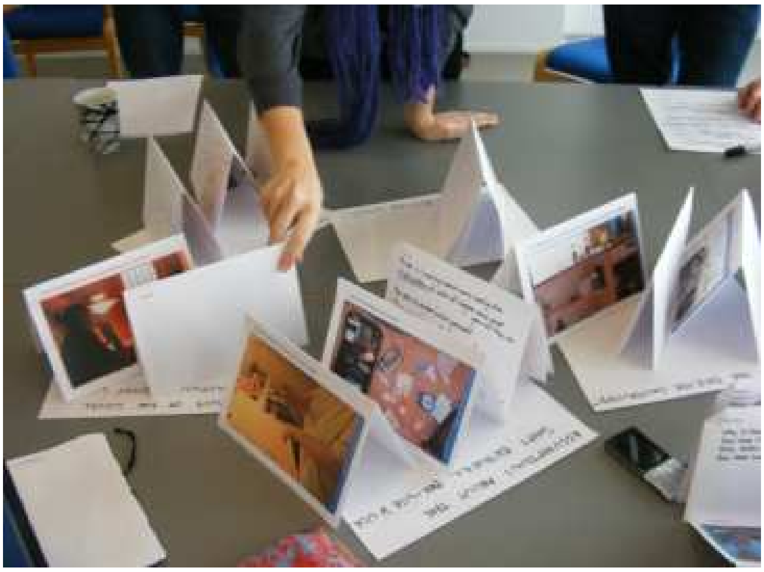
> Connie: In my nearest future, my blood sugar will be high, and I will go on insulin. I think there will come a time, where I can no longer live without insulin [...] I have just started a new medication from Novo Nordisk. I am doing very well with that. It is an injection, but it is not insulin, I hope I can live with that for some years.
>
> Ditte: What is your reason for thinking you will go on insulin; did the doctor tell you that?
>
> Connie: No, this is the normal way for diabetes – in the end you always get insulin, and you stop producing insulin.
>
> Ditte: And how do you feel about that?
>
> Connie: Bad, I do not like it, I think it is the end of my life. It is the scariest thing I can imagine. When I will go on insulin, it will be the end of everything. I will not be able to get of it again. My condition is – once I get insulin, there is no way back. As long as I am, where I am now, I can lose weight, I can do more exercise, and then I will get better, but if I get insulin, I cannot get better.
>
> [...]
>
> Mona: I have the opposite expectations for the future than you, because, I take some pills for the diabetes, and since my stroke, I have exercised regularly three times a week, and that is the most important for me now. And now my blood sugar is very, very fine, both the long term and the one you measure at home. So I hope to get rid of the pills, and it will give me some freedom. As I told you when you [Ditte and Janet] visited me, I hate to take pills, it is the most disgusting thing – sometimes I feel like throwing up, and I hope very much to get rid of the pills.

The two women oriented to different imageries of the future as they relate to their diabetes. Connie pictured her condition as an inevitable decline, marked by the type of medication she gets. At this point in time, she was injecting herself with the anti-diabetic medication GLP1 at home, yet shifting to insulin was the scariest thing she could imagine; it marked the point at which she would no longer be able to ‘get better’. She imagined having an increasingly limited capacity to control or improve her condition. As long as she was not on insulin, she might be able to make an effort and get better; in the future she would be unable to do so. She drew a distinction between getting better prior to insulin, which she might be able to affect, and the prospect of her body becoming unable to produce insulin, which she cannot avoid. Mona, in contrast, believed in the possibility of countering the progression of her condition. In a study of genetic counseling for cancer, where patients are faced with future risk of severe illness and death, Svendsen shows how some people deal with risk by transforming their future horizon (2003). In one case, a woman reinterpreted her future in the context of her previous luck in life; she refused, Svendsen argues, to allow risk and prevention to colonize her future. Unlike cancer, diabetes is figured as a condition that can be countered, and Mona talks about hard work, exercise, compliance with treatment and controlled blood sugars as a way of establishing hope and freedom as her future horizon. The two imageries Connie and Mona bring about are pictures of two opposite futures: one of certain degradation and one of hopeful improvement. They reflect different ways of relating to the future; Connie imagines herself following the 'normal' course, while Mona is dedicated to getting better so her diabetes will not advance.

The virtue of 'control'

Understanding and negotiating the capacity to act against the diabetes, and not only be acted upon by it, concerned most of my informants. In another workshop, further into our project, we asked participants to engage in a co-analytical activity. We presented extracts from dialogues and stories from our fieldwork. The intention was to encourage discussions about some of the problems and dilemmas of treating diabetes. The immediate responses were surprisingly negative and largely related to a 'right' way of dealing with diabetes, echoing the imperative to live healthily and take active part in monitoring and treating diabetes. Among the stories we shared was Mona's story of hiding her pills and assistive technologies so that she would not feel like a patient. When we asked participants to give headlines to our empirical material, they chose words like 'denial' and 'ignorance', and did not suggest another possible story about people who did not want their lives to be colonized by diabetes treatment. In the ensuing discussion, the contrast between denial and taking responsibility, was supplemented with a 'grey zone' by one participant:

> Benny: It is really hard for me to understand if you get a problem of this kind, that you do not take responsibility, but I can imagine that some people don't, I mean we known that is the case... But it can have some serious consequences, if you don't do something about it.
>
> Steen: You are often made aware of those serious things that may occur as complications. I think it is too much. It is lurking as a grey zone in the future: will you be one of them? Or what is the risk that you get complications? I would like a more positive approach in diabetes to the entire treatment of diabetes. I know you need to be realistic, and they might come, and maybe



During the workshop, we presented participants with stories and pictures from our field.work, and asked them to analyze them and organize them thematically

> they will to some degree… But I do however think that since it is a condition that you may influence so much, together with your doctor, that we could have a more positive focus in the treatment. The magazine of the diabetes association is very focused on cases about negative things, such as dialysis, kidney failure, and silicone feet and so on.

Benny points out that diabetes may have consequences ‘if you don’t do something’. However, as Steen remarks, even if you do all you can, one is never free of this potential danger. The interpretation of responsibility is problematic because of the absence of causality. The message in much diabetes communication is that you may have to have your feet amputated or suffer other complications. In this light it seems difficult to transform the future to a hopeful horizon; it seems impossible to get free from the grey zone of constant uncertainty. Benny engages with Steen in a search for transforming this grey prospect to something more positive:

> Benny: Once your condition – I believe it is a condition – is well regulated, you feel better. That might be an argument for exercising and taking the medication. I can feel that I am actually getting better, not only as a matter of conscience, but also physically.
>
> Steen: That should be one of the main goals; I mean to feel that well-being.
>
> Benny: I believe it is a strong argument.
>
> Steen: And you get more energy then you had before.

They search to translate diabetes from an uncertain future to a secure present. Benny observes that a consequence of well-regulated blood sugars is that one feels better. In this image, diabetes is a disease that may be regulated, and you may be rewarded for the effort. Steen takes this observation, and reframes the treatment goal so it is not only a matter of blood sugars but also the stage of well-being. According to Cohn, diabetes is characterized by a notion of risk as something latent in the future, while there is a lack of specific causalities, which gives rise to a great flexibility of interpretations (2000: 210). Jan, another participant in the workshop, disagreed with the importance of changing behavior. He proposed another image of diabetes and its treatment:

> Jan: The first thing you need to do is regularity. That goes for all of it: the pills you eat, as well as when you are going to see your doctor for your check up, you must be fasting, otherwise it is a waste of both yours and the doctor's time [...] The important thing about the measurements is that they are okay as they are, and that you get the medication it takes to keep it [the blood sugar] on the level you want it to be at. And then, eh, you may say, as long as it is stable, then I have no intentions about changing anything, because it is as it is. I do not consider it a disease either. I think of it as a food supplement, that you get so that your well-being can become better, and you can get a better life, a healthier life or what you want to call it.

Jan's position was somewhat provocative for other participants in the workshop, who argued that lifestyle changes were still important even if numbers could be regulated with medication. However, well-regulated numbers was an indicator that many people used to assess their own efforts in treatment. Many of the stories people told me, and the images articulated in the workshops related to the issue of balancing being in control with being able to live their own life, so everyday life was not transformed into a series of treatments and lifestyle changes. So even if my ethnographic material was dominated by the virtue of control, it was articulated and interpreted in a variety of ways.

Through practices of relating to the medical conditions in social contexts other than the clinic, they took on other shapes. Hearing loss emerged as a matter of interpreting and separating matters of hearing impairment from matters of paying attention, being absent-minded or the natural process of an aging body. It was not only a private sensory matter but located in the consequences of interactions. In diabetes, the difficulties of transforming and balancing between the virtue of control and the authority to live what to the person with diabetes considered a normal life were interpreted and negotiated in various forms.

CONCLUSION

I started this chapter by approaching the home setting as another site for practically handling medical conditions, rather than a site fundamentally different from the clinic. What struck me, however, was the apparent difficulty of observing how people deal with their conditions. The invisibility and difficulty of 'feeling' their medical conditions, was a starting point for understanding, when and how the conditions would emerge as problematic and in need of action. I have argued that hearing loss emerges as a relational condition through disruptions of everyday activities, and is specific both to the situation as well as to other people's ability to hear. In the handling of diabetes, home measurements are central. However, measuring does not only produce a number on a display, but forms the basis for setting tangible goals, reducing distant time horizons to specific points in time, and make for a very concrete way of keeping the disease in control.

The chapter is both an analysis of how people handle their conditions, and an investigation into the notion of practice. The accounts I elicited through interviews were not only descriptions of events; they were stories composed by the informants in situ by selecting and interpreting situations, relating them to understandings of medical conditions, self and others. In this sense, events were 'taken'. As a consequence, I broaden the notion of practice from what is *done* as the diseases are enacted and subsequently reported on in descriptions, to incorporate practices of marking and connecting those events. I supplement the focus on observable and reportable situations in which the conditions emerge, with a focus on the meaningful interpretations and transformations made by people as they deal with their medical conditions. I started out by following Mol's recommendation of leaving intentions and interpretations behind, but consistent with Dewian pragmatism I suggested that practices only become meaningful because they are ordered and organized through reflective analysis and reacted to intentionally. People not only take part in interactional enactments of their conditions, they actively engage in dealing with them from a situated concern. They are doubtful, hopeful and intentional.

In situations where people interact, I observe that their interpretations and transformations are subject to negotiations. In the field of hearing impairment, explaining disruptions and placing the consequential responsibility for repairing or avoiding them are matters of shared analysis. In diabetes care, the moral imperative to 'control' the condition is interpreted and transformed in many ways. Health discourses do not determine interpretations, but give rise to people's problems and dilemmas.

Displaced from the clinical context, situational differences and contrasts among different versions of the medical conditions are rendered visible. At the same time, contrasting versions of subjectivity also emerge. In the clinics, patients are ascribed ability to know their sensory experience of hearing loss and their everyday efforts to treat diabetes. Living with hearing loss some people skillfully compensate for their impairment, they pre-empt it by changing the situation and their social habits and they negotiate the meaning of hearing loss and responsibilities for repairing it. The epistemic authority ascribed in the clinical context is up for negotiation and interpretation in the family context. While living with diabetes, some people strive to take control of their condition, others become vulnerable to its unpredictability and still others actively transform their condition so they no longer think of themselves as ‘patients’. As these practical activities unfold and change, different subjectivities emerge as a result of interactions.

CHAPTER FIVE

CONFIGURATIONS OF TREATABILITY

In the previous chapters, I have unfolded the ways in which hearing loss and diabetes emerge and change through practices of measuring, handling, marking, connecting and transforming. I have described doctors, patients and family members, not as *spectators* each with their own perspective on hearing loss or diabetes, but as active *participators* in a social and material world, who deal with problematic situations. On each occasion the medical condition is assembled slightly differently, and there are ‘as many kinds of known objects as there are kinds of effectively conducted operations of inquiry’ (Dewey 1929:157). With my movement among different interactions, the specificity and partiality of each setting is rendered visible. In this chapter, I argue that practices of inquiring, locating and solving problems are inseparable from possible solutions; a problem emerges in relation to its solutions. I am particularly interested in the hearing aid and insulin as solutions, and in what happens to the medical conditions when they are related to these solutions. As Keller observes, ‘we need to understand the enmeshing of representing and intervening, how particular representations are already committed to particular kinds of interventions’ (1992:76). This suggests that particular and partial versions of hearing loss and diabetes are presented in relation to hearing aids and insulin; that only certain features in the myriad of ways people meaningfully produce health conditions are represented in commitment to the treatment devices.

From here, I want to examine the impact of technologies on the meaningful production of medical conditions. Through the past chapters, I have presented a variety of methods for handling with the medical conditions and rendering them meaningful. From this diversity of enactments, I show how the treatment technologies draw attention to particular aspects of the problems people are dealing with. I return to the concept of configuration and depict the treatment technologies as *materialized configurations*: I stress the prefix *con-* as it indicates that meaningful associations are formed in relations *with* humans (Suchman 2007). As for the rest of my thesis, I will stick to actual occasions in which bodies, conditions, measurements and treatments are related to each other, to explore how treatment technologies shape the conditions they are designed to treat. In other words, I am interested in how treatability is figured *with* the treatment technologies.

Before I start my analysis, I will discuss the relation between problems and solutions in the medical anthropological literature. I will then examine occasions of clinical interaction, where the hearing aid or insulin is introduced as possible treatment. As I did in chapter three, I will focus on conflicts or mis-alignments between different versions of the conditions. Such conflicts unbracket the interactional work of creating coherence (or establish incoherence) between the medical conditions and the solution provided by the technological treatment devices. While I argue that technologies are designed to solve particular problems associated with diabetes and hearing loss, I also observe that people relate differently to these devices. Through my analysis of treatability, or how diseases are made relevant to treatment (or not) , I reconceptualise a ‘treatable disease’ from a physical state in the body that is responsive to medical intervention, to an effect of relations between bodies and technologies, and between patients and their doctors.

PROBLEMS AND SOLUTIONS

The original framing of this research project was formulated as a study of the movement (or lack of same) from pre-use to use. From here the companies asked me what prevents people from seeking help and starting treatment. In other words, what hinders the rational movement directed towards treatment and recovery? Like many other studies in health care, these questions assume what Good (1994) has called the ‘medical model’; the understanding that diseases produce ‘symptoms’ experienced and expressed by the patient, and ‘signs’ of abnormality that can be measured and examined by a clinician. Based on symptoms and signs, doctors identify the underlying disease entities and provide a diagnosis. This allows for ‘rational treatment aimed at intervention in the disease mechanisms’ (ibid:8). Inherent in the ‘medical model’ is an assumed temporal sequence of events; *first* a disease occurs, *then* it produces symptoms and signs for the doctor to investigate, and *finally* a diagnosis is given and treatment begins. Keeping Keller’s advice in mind, we may observe that the temporality of the 'medical model' masks the interdependence between a disease and its treatment(s) and ignores how available treatments impact the transformation of the medical condition into solvable problems.

Medicine as a 'driving force'

In contrast to the 'medical model', Ecks suggests that we see medicine as a 'driving force' in a reversed model of the process of falling ill (2013:8f). Starting with the drug, he argues, we may explore how an active ingredient *first* is developed to target a specific disease. *Then* the industry markets the curable symptoms to doctors and patients. In this reversed model, falling ill is a matter of recognizing the described illness' symptoms and seeking help. As a consequence, manufacturers and distribution channels play a crucial role in the emergence of a diagnosis (ibid.). In accordance with this model, Greene traces the historical development of disease categories in diabetes care, and links the distinction between type 1 and type 2 diabetes to the launch and distribution of the first oral antidiabetic treatment, marketed under the brand *Orinase* in the 1950s (2008)[1] Prior to the launch of Orinase, the most frequent treatment for diabetes was injection of insulin. When Orinase became available, it was soon discovered that, unlike insulin, it had no efficacy in young children, and seemed to work best in older, overweight patients (ibid:90). Greene observes that the responsiveness to Orinase was used in the field of medical research to support the evidence that type 1 and type 2 diabetes were 'different metabolic disorders' (ibid:91). He concludes that our contemporary understanding of diabetes is strongly influenced by the manufacturing and marketing of pharmaceuticals. Greene disassociates the emergence of disease categories from local, clinical practice. In his analysis of the impact of new measuring technologies and treatments in diabetes care, he argues that the patient's 'symptoms' offer a first-person perspective, while 'signs' are the second-person perspective of the doctor observing the objective pathology of the patient's body, and 'numerical definitions of pathology offer a detached, third-person perspective, seemingly independent of both doctor and patient, connected instead to the anonymity of measuring devices and expert committees that define standards, thresholds, and guidelines' (ibid:8). In this approach, the doctor-patient relationship is re-shaped and new processes of 'patient-hood' are generated with the distribution of measuring devices and medical treatments (ibid:9). What used to be a craft of clinical practice is giving way to doctors 'prescribing by numbers' (ibid.). In this argument people do not move from an observation of symptoms toward available treatments; treatment makes disease categories possible and pathology is detached from the patient's experience of symptoms and the doctor's observations of signs, defined by measuring devices and guidelines.

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[1] Orinase belongs to the group of antidiabetics sulfonylurea that increase the release of insulin from the beta cells in the pancreas (Christiansen 2014a).

My examination of medical practice in chapter three depicted a situation that differs both from the temporal sequence of the medical model, in which people fall ill, seek help, and start treatment, and from the reversed model in which medical technology is a 'driving force' that independently of human actors reshapes patient-hood and disease categories. I showed that doctors are not faced with 'signs' and 'symptoms' as merely 'givens' that allow them to reveal disease entities. 'Signs' are the result of an embodied practice; of interactions between tools, bodies, practices, professionals and patients. 'Symptoms' do not neutrally reflect experiences, as they too are 'taken' as part of the situated inquiry. Finally, disease problems are not determined by guidelines and measuring tools, but enacted in a multitude of versions. In light of these observations, I approach treatment technologies, neither as rational treatment that simply intervenes in the disease mechanism, nor as a 'force' determining disease categories detached from local interactions, but in terms of the ways in which people relate and react to hearing aids and insulin.

Technologies-in-practice

In a review of the sociological literature on medical technology, Timmermans and Berg critique of what they term 'technological determinism', where technology is pictured as a driving political force and sociological analysis builds a case against 'medical hegemony'(2003). They point out that this deterministic approach ignores the fact that people *use* technologies differently; a medical technology that may in one case give rise to alienation of the body, does not necessarily do so in another (ibid:100). They argue for a study of 'technologies-in-practice', according to which technologies should be studied in their embedded relations (ibid:104). From this stance, medical technologies are treated as *mediators* in 'the construction and production of novel worlds', as they co-produce novel subjects and bodies without determining them (ibid:108). It is precisely the practices of relating, in situ, to medical technologies that interest me. I want to explore, how diseases are locally transformed as they are related to available solutions.

Van der Geest and colleagues (1996) argue that medicine, with its 'thinginess' provides patients and healers with a tangible weapon against diseases. The concrete and usable treatment holds promise of an effect and has the ability to transform dysphoria into something concrete; 'practicing medicine, after all, is the art of making dis-ease concrete' (ibid:154). With the concreteness of medicines, diseases are transformed into solvable problems. However, this same concreteness of treatment technologies may also set a 'trap'; as Ingold observes, 'by presenting a problem in the form of what appears to be its solution' (2012:20). He wonders about the treatment of hearing impairment: 'is the hearing aid [...] [a] trap that sets a problem in the form of its solution? Like the spoon that forbids us to hold the bowl to our lips, does the aid determine that we should always hear at a distance? Why should we not simply grow accustomed to inhabiting a quieter world?' (ibid:31). Suggesting that a technological treatment sets a 'trap' points not only to the tensions inherent in becoming a user with all the requirements and practice it takes, but also to the relations to other solutions. As I have shown, there are many ways of handling hearing impairment and diabetes, and the problems people deal with extend far beyond fading sounds and high blood sugars. In the following, I will examine how the treatment technologies form part of the construction of treatable medical conditions. I situate hearing aids and insulin injection devices embedded in practices of relating as they unfold in the clinical encounter.

My approach constitutes a particular attention to the sociomaterial circumstances of treatable conditions, which differs from the medical anthropology concerned with 'the social life of things' (Appadurai 1986). With their methodological proposal of a 'biographical approach' Van der Gest and colleagues follow the transactions and 'social life' of drugs as a way to address the cultural construction of the body (1996:153,156). I am not going to follow the 'life cycles' (ibid:153) of hearings aids and insulin injections, as they are produced, distributed, purchased and used, but will explore the practices of relating to treatment technologies as a locally situated, interactional phenomenon taking place in the clinics, I visited. Attending to particular occasions in which hearing loss and diabetes are or are not rendered relevant to treatment, I examine how the medical conditions are figured with the treatment technologies. I argue that treatable conditions are figured with the treatment technologies, yet not determined by them. As Gubrium and Holstein observe, objects – such as treatment technologies – have an indeterminate quality, because they are ascribed a variety of meanings as persons engage their worlds (1993:655). In spite of this variety, however, there is also a regularity in the process of attaching meanings (ibid:656). This allows me to examine treatment technologies as embodying shared meaning (Harraway 1997:23), yet indeterminate as objects (Gubrium and Holstein 1993).

MOMENTS OF TREATMENT

I have earlier argued that the moments of 'initiation' of insulin and the 'purchase and fitting' of hearing aids were granted great importance in the companies. Depicted as the moments where treatment commences, they were deemed moments of key importance and located in a sequence of events, where treatment choice is assumed to be followed by the onset of use. So far, I have paid little attention to these moments. From the conviction that the transition to use, does not happen in *one* moment, but in an ongoing process, I have explored the practices of dealing with the medical conditions more broadly. Inspired by Mol, I have argued that care is an ongoing process in which doctors and patients tinker with different solutions, and that choices are rarely enough to carry out a treatment plan. In turning to ‘moments of treatment’, my intention is to explore what happens when treatment devices are introduced as a solution in the clinical encounters. I do not depict these ‘moments of treatment’ as pristine moments that determine an ensuing sequence of events. Instead, I examine them as actual occasions in which bodies, medical conditions and treatments are linked as part of a practice of inquiring into and handling diseases. What follows is my analysis of occasions in which a hearing aid or insulin was brought in as a solution. I attend to representations of hearing loss and diabetes that emerge in these ‘moments of treatment’ committed to particular interventions (cf. Keller 1992). Each occasion is introduced by an illustrative comment by a doctor or patient.

‘A hearing aid has to be a part of you’

In an ear, nose and throat clinic outside Copenhagen, Anna greeted her patient, 66-year-old Eva. She had been referred to the clinic by another doctor, who recommended that she be fitted for hearing aids. Anna started the consultation by asking Eva about hearing-related problems in her everyday life. Eva explained that she did not have many problems on a daily basis; in her job as a receptionist, she only occasionally had problems hearing what was being said on the phone, but her daughters had repeatedly encouraged her to have her hearing tested. Anna started examining Eva’s ears, while she telling her about the process of getting hearing aids:

Anna:	You need to say to yourself: If I am to get a hearing aid, then you need to be prepared that the aid must be used every day, as a part of you.
Eva:	Yes.
Anna:	That is to say, you need to feel that you will put it on, maybe not all day, but at least many hours a day. And particularly in the beginning, when you start with the aid, then you cannot – because, some people would say ‘I do not hear well when I am at parties’, then I will say ‘but you do not put on a tuxedo or nice dress and then a hearing aid that you only use every second month’.
Eva:	No.
Anna:	That is not going to happen.
Eva:	No.
Anna:	So a hearing aid has to be a part of you, and you need to be at a point where you need it on a daily basis for it to lead anywhere. Otherwise it will be a bad conscience lying in the drawer, right?
Eva:	Yes.
Anna:	’Eh, I ought to wear it’, but if you do not really need it, and you are not at a point where you would say ‘I am at a point where I cannot hear’, then you are not going to put it on.

Eva (left) and Anna (right) read Eva’s audiogram.

Prior to the encounter, Eva had taken a hearing test. Anna picks up a printed copy of Eva’s audiogram.

Anna: So, I would say, when we look at your hearing test - normal hearing is all the way up here (*Anna points to the audiogram*).

Eva: Yes.

Anna: You can see that you hear perfectly normally up to 2000 hertz, and what does that mean? I usually compare this to a piano, you know the lower tones bom bom bom, and then it goes up octave by octave.

Eva: Yes.

Anna: And right and left ear – they are marked with cross and circle, so that means, as you can see, the crosses and circles go together. So for all practical purposes, you hear equally well on both ears.

[...]

Anna: Next thing is - So what is normal? You may say that when you get into your 40s or actually it starts from childhood, I do not even know when it starts, but we constantly lose a tiny tiny bit of our hearing and that starts in the treble, so as you grow older, then (*pointing to the audiogram*) this is what I called the bass and then the treble, and this is good hearing and this is bad hearing, so as you can see there is a drop.

Eva: Yes.

Anna: And that is to say, if you went to Mallorca with your children or somewhere else, and they would say ‘can you hear the cicadas mom?’ ‘No’.

Eva: Okay.

Anna: You need it at a higher volume, that is to say, you need to get closer.

Eva: Yes.

Anna So you might say, your hearing is not gone, you just need a higher volume in the high frequencies, right?

Eva: Yes.

[...]

Anna: So for all practical, how to say, purposes, you hear within what we would say is almost normal, and from my, in my opinion, I would not recommend anything.

Eva: You wouldn't? I need that in writing *(they both laugh)*

Anna: Yes.

Eva: I mean, I have to go home and show it to my daughters and tell them it is not good enough yet.

When Anna warned Eva that she needed to make a hearing aid a part of herself, treatment is articulated as a matter of commitment. From here, Anna asked Eva to consider how she felt about her hearing; if she was at a point where she 'could not hear'. It was less relevant if Eva's daughters observe that there are sounds, like the cicadas she cannot hear, says Anna, but crucial if Eva felt personally bothered by her hearing. In the consultation with Svend, a similar argument was made, as Sebastian repeatedly asked Svend to assess the amount of personal annoyance the hearing impairment caused him, and explained to Svend that he needed to feel bothered in order to use the aid.

In both these moments of treatment, the doctors describe hearing impairment as a matter of personally experienced problems that must be serious enough for the patients to desire treatment. If the patient does not feel bothered by hearing problems, the aid may become a source of what Anna terms 'bad conscience'. While the advanced technology of the hearing aid makes it possible to treat high frequency hearing loss, the low tech requirements of putting the aid on every day, keeping it clean, changing batteries and not forgetting it in the drawer, produces a treatable hearing problem as something that must be found to be problematic enough to merit a continuous effort to treat it. For this reason a treatable hearing loss is a problem that needs treatment 'on a daily basis' as Anna observes. The expression 'leaving the aid in the drawer', was often used to describe failed treatment amongst my informants. It may be a coincidence that the words 'disappoint' and 'drawer' are spelled the same way in Danish[2], but in any case this phrase points to the obligations inherent in becoming a user, and the potential inability to adhere to the demands of the device becomes a reason not to use it.

Another interesting observation in this moment of treatment is the work Anna put into establishing that Eva's hearing is 'almost normal' despite 'a drop' in the hearing curve. The measurable drop is presumed to be normal given Eva's age. The normalness of Eva's hearing

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[2] Both words are spelled "skuffe" in Danish.

establishes it as non-treatable, and Anna alternates between solutions, equating Eva's need for 'higher volume' with a need for getting 'closer'.

As Anna made these observations, Eva listened, and when Anna reached her conclusion and made her recommendation, Eva smiled, laughed and was thrilled to hear that she did not need treatment. Eva asked Anna for written documentation that her hearing was normal so she could bring it home as evidence.

'You are not paying attention'

The emphasis on the personal hearing experience is often associated with an epistemic authority of the patient to know his or her own hearing and the right to make the decision about starting treatment, as I observed in chapter three. In the following case, however, we will see that the measuring and treatment technologies, in production of a non-treatable hearing impairment, may result in different rights and responsibilities for the patient.

On another occasion in Anna's clinic, a patient, Anders presented a concern regarding his throat. Anna told him about my study, and Anders mentioned that he has difficulties hearing, and that his wife has been asking him to get his hearing tested. Since another patient had cancelled the next appointment, Anna offered Anders a hearing test. When the test was completed, they read the result:

Anna:	You have had a hearing test. I usually tell people, when you look at this kind of curve, the good hearing is up here, and bad hearing is down here. The numbers here are decibel, and you can kind of compare it with a volume control: how loud do I have to turn up the sound for you to be able to hear it?
Anders:	Okay.
Anna:	Good. And you can see, most of the measures, we have, are – you are better than twenty and ten and they are supremely fine, great, normal…
	Anna continues explaining the audiogram with the analogy to a piano.
Anna:	Good. So we may now ask: Can this explain that you feel you have problems with your hearing? Then I would say, I do not think it can. Imagine that a hearing aid lifted this note up to the other, then my verdict is that, you would not hear better.
Anders:	No.
Anna:	That is to say, it would be minor. So by and large – your left ear is even exceptionally well hearing, also comparing to the hearing loss we usually get with the age.
Anders:	Okay.

Anna:	So, we would say, you hear normally [...] That is to say, you do worse with the good hearing you have, than the average person does. But a hearing aid that gives you more sound into your ears that would not help you at all.
Anders:	No, no.
Anna:	So, we can say there are some – how to say it – some good advice, you know that… One should make sure to look at the people, who are talking and eventually move a little closer to the person one talks to, and also try to reduce the background noise.
Anders:	Yeah, yeah.
Anna:	And so on and so on, and then there might be something about, if one is, er… There is something about concentration, right? If one is thinking about something else, then somebody can be talking to you and you do not hear it, not because you do not hear, but because you are not paying attention, right? It is not because one is not able to hear it.
Anders:	No, no.

This was one of the few moments of treatment I observed, where the doctor made the patient responsible for his hearing. In most consultations, the patient experience was used as a way of pulling together a more complete picture of the hearing impairment. But since the test showed that Anders heard ‘fine’, and even ‘exceptionally well’ in his left ear, the experience and medical evidence did not produce a consistent picture. The audiogram showed that a hearing aid could not solve his problem, as Anna observed. This reading divides his hearing between a physical ability which is normal, and a sensory experience, which is the result of Anders doing ‘worse with the good hearing’ he has, than ‘the average person does’.

The measuring technology together with the treatment device, takes part in the figuring of Anders’ hearing problem. He might have a hearing problem, but not one that the aid can solve. Anna suggests hearing techniques: ‘look at the person who is talking’ and ‘move closer’, but she also suggests that it could be a matter of concentration and paying attention. The epistemic authority that I described earlier, is here reversed from a right to know what one can hear to an individual obligation to listen.

Hearing aids and other solutions

These examples of clinical interaction suggest that the aid represents the problem it solves. The hearing aid is designed to amplify surrounding sounds as they enter the auditory canal. Relating to this solution, certain features of the impairment are brought to the fore and hearing is represented as a physical loss of the ability to hear, solved discreetly on the body of the impaired person. It requires an effort of the user to wear, which is related to as an obligation or a freedom to decide. Since not all kinds of hearing loss can be treated with a hearing aid, the device also forms part of the figuring of normal hearing and normal efforts to hear. The hearing aid mediates the construction of treatable and normal hearing impairment. However, the hearing aid also has an indeterminate quality as people relate and react differently to the treatment technology.

All clinical encounters are interactions of doctors, patients, bodies and technologies in specific settings, and insofar as available solutions deem certain problems to be relevant to treat, they do not determine this to be the case. Attending to technologies-in-practice shows us that relating is a situational accomplishment. Not all doctors related to the aid as a solution that required daily use. In the consultation with Svend (see chapter three), his doctor, Sebastian, explained that using a hearing aid is optional and there was no obligation for Svend to make it a part of himself; he could choose if he wanted to get the aids, and how much he wanted to use it. The relation between the aid and other solutions were also treated differently. With Anders, hearing techniques were positioned in opposition to hearing aids; they were needed because his hearing loss would not respond to amplification.

In another case, I was with an audiologist and her patient who had recently been fitted with hearing aids but was disappointed with them. They discussed his difficulty with hearing the TV and with following conversations at a dinner party, particularly when there was music or noise in the background. Unlike the practice I described earlier, this conversation about problematic situations was not only a matter of mapping out hearing problems to inquire the relevance of *one* solution, but about relating different problems to different possible solutions. The clinician agreed that voices on TV are hard to hear and recommended a subtitle service for her patient. As for the dinner parties, she asked him if he felt comfortable asking the hosts to turn down the music, so that he would be able to hear better. She pointed out that even with a hearing aid, some situations would always be difficult. In this case, the aid did not set any ‘trap’ (Ingold 2012) for other ways of dealing with hearing impairment; it was not a matter of either hearing aids or hearing techniques, but of making the most of alternative solutions. She addressed his hearing impairment, not only as a matter of inability to hear certain tones, but also as a sensory impairment that can be aided by using vision, and as a matter of asking other people for help.

On another occasion the relation between the hearing aid and other solutions was brought about more subtly as a patient, Bente, compensated for her impairment in a conversation with her doctor Sebastian. At the urging of her husband, Bente had come to the clinic to have her hearing tested. After the completion of the hearing test, Bente and Sebastian sat down to discuss the result. The audiogram on the screen showed a dropping curve, and Sebastian explained that Bente’s hearing loss could be ameliorated with amplification. Bente, from the other side of the table, leaned forward, looked at him and cupped her hand behind her ear to hear what he said. In

The audiogram shows the decline in Bente's hearing, and Sebastian explains the benefit of hearing aids. At the same time Bente leans forwards and cups her hand behind her ear.

praxiographic terms they simultaneously enacted different versions of the impairment. In this moment of treatment Sebastian represented hearing impairment as it was rendered visible in his professional vision: from the curve on the screen and Bente's reported problems, Bente simultaneously engaged in her everyday practice of dealing with hearing loss, reminding us that 'people can do a great deal to enhance their hearing that manufactured devices cannot' (Ingold 2012:31). In the following, I will describe the introduction of insulin as a possible solution to the problems of diabetes.

'You can change your body, or we could consider insulin'

Olga is one of Jens' type 2 diabetes patients. Like most of his patients, she comes to the clinic for regular visits with a nurse every three months. I met her when she had come for her annual checkup. She was 78 years old and had had diabetes for seven years. Jens opened the consultation by asking how she was doing, to which she responded that she was fine. They talk about her diabetes and her seven medications. Jens then turned to her blood sugars, and as he was looking at the computer, he said:

Jens: When I look at your numbers, as far back as I can see, including the most recent test, then it is a little high.

Olga: I know, and it is constantly high, it is always around nine.

Jens: Yes, and the ideal is to have it under seven. Can we get down there?

Olga: I don't know. I think we have tried everything.

Jens: N-yeah.

Olga: You have adjusted the pills and things like that right?

Jens: Yes.

They talk about what she has done to change diet, exercise and lose weight. She has been losing weight over the period of time and when he asks her to step up on the scale they conclude that she is still losing weight. Then Jens presents her options.

Jens: There are kind of two approaches to the blood sugar. One is to change the body, and you are working on that by losing the extra kilos. And the other is to make the muscles work and burn some sugar, right?

Olga: Yes.

Jens : And then there is the medical way, which apparently- what we have done now, does not help so much.

Olga: No.

Jens: So we could consider giving you insulin.

Olga: I would rather not have that.

Jens: Why is that?

Olga: Because it is really easier with the pills.

Jens: Well, it is also easy with insulin.

Olga: Yes, but I have a friend who injects, I do not know how many times a day, and she does it by herself. But okay, she has diabetes one, so that is different.

Jens: Actually it is not as complicated as many people think.

Olga: Are you not more dependent on it, than you are on pills?

Jens: What do you mean by 'dependent'?

Olga: Well, if you are travelling and such, it is easier to bring the pills for those days.

Jens: Yes, is it not easy to bring the insulin too?

Olga: I don't know, I have not tried it.

Jens: No.

Jens is searching in a drawer and takes out an insulin injection pen.

Olga: That is similar to the one I use for blood sugar measuring.

Jens: Yeah. This is a pen and you turn here to adjust the amount of insulin.

Olga: That is the same too.

Jens: Then you twist the needle on, you stab yourself and press down the piston and then it is done.

Olga: That is actually the same system as for measuring blood sugars.

Jens: Except you do not stab your finger with it.

[...]

Olga (right) and Jens look at the insulin injection device.

Olga: Once you start insulin, you need to keep on with it, right?

Jens: That is no different from the pills.

Olga: What if it [the blood sugar] then drops?

Jens: It will. That is the point. You start carefully and then gradually increase the dose until you get at the level you want to be at.

Jens assures her that a nurse will teach her to inject and to monitor her blood sugars more carefully at home.

Jens: Since you are fit and only 78 years, and might have to live with diabetes for many years to come, it might be worth the effort to get it [the blood sugar] all the way down to where we want it, to long-term values below seven.

Olga sits quietly on her chair and looks at the floor for a while.

Olga: Must I decide today?

Jens: No I don’t think so. You should be allowed to think about it-

Olga: -and see how it looks next time?

Jens: Yes. I am not sure if next time should be in three months or if we should say one month... Then you could try and make one or two of those baseline 24-hour tests, as I call them, where you measure blood sugar four times.

Olga: Morning and night-

Jens: In the morning before breakfast, and then one hour after each meal, in order to sort of practice that part of it.

Olga: I can try that, and then maybe go down to the running machine a little more.

Jens: Yes and then think about whether it would be good to get it regulated all the way down where it must be.

In this case, the need for increased medical treatment emerged from the ‘constantly high’ blood sugar Olga had. What followed was a status of the efforts they had already made to lower the numbers: adjustment of medication and weight loss. As Jens explained, there are ‘two approaches to blood sugars’, and he depicted lifestyle changes and medication as separate solutions to the same problem of high numbers. Based on the conclusion that the current efforts ‘do not help so much’, he introduced insulin as an alternative. In this moment, the treatment goal is about numbers, while other concerns often addressed in diabetes care are left out. In Jens’ observation the current treatment was not enough, the high numbers were attributed to inadequate efforts, and this was heard by Olga as a last chance to ‘change the body’ by spending more time on her treadmill before insulin became inevitable.

In other situations, I had heard doctors and patients identify numerous causes of the onset and progression of diabetes, including genetic predisposition, stress, and hormonal imbalance caused by night work. On one occasion I observed, a patient who had well-regulated sugar levels and expressed doubts that he was ill, to which his nurse responded: ‘There is no doubt that you have diabetes, but you have very well regulated diabetes. However, the nature of diabetes is unfortunately that, even if you do all the right things, it will require more and more medication’. The nurse used the ‘nature of diabetes’ to convince her patient that he had a diagnosis even though his numbers indicated otherwise. In the conversation between Jens and Olga however, the progression of treatment was oriented to the insufficiency of previous treatment. Olga did not hear Jens’ suggestion about insulin as inevitable even if she was ‘doing all the right things’, but related to Jens’ suggestion about insulin as a last opportunity to do something about her long-term blood sugar level by ‘changing her body’. She asked for more time to reduce her weight and lower her blood sugar numbers, whereas the insulin marked a point of no return.

Both Olga and Jens oriented to insulin as something very different from the tablets and lifestyle changes; Olga by raising her concerns about dependency, administration and permanency, and Jens by stressing that learning to take insulin required time and practice to learn. The onset of insulin was related to as a ‘decision’ to be made sooner or later by Olga, when she asked if she ‘must decide today’. Jens was working to persuade Olga that administering insulin is not as complicated as she may think and encouraged her to start more closely monitoring her blood sugars as part of the insulin treatment. Olga however wanted more time for the other treatment options. In this configuration of diabetes care it is difficult for Olga to opt against the treatment goal of ‘bringing the numbers down where they *must* be’. In a comparative analysis of solutions to health issues, Jöhncke and colleagues describe health interventions in terms of ‘social technologies' (2004). With this terminology they point out, firstly, that interventions are a practical art situated within social relations, and secondly that they bear an intentionality of shaping the social in a particular way. As a consequence of this intentionality, social technologies are directed towards certain understandings of the good life, and are thus morally consolidated, as not only useful but also 'correct' (ibid:391). Social technologies therefore orient to culturally defined principles that are difficult to oppose, including principles about curing, normalizing or saving lives, and carry with them a moral imperative (ibid:391). As I showed in chapter four, patients transform these imperatives about healthy living, so their everyday lives are not colonized by the treatment of diabetes. In this clinical encounter, however, where numbers are high and other treatment options have been exhausted, it is difficult for Olga to oppose the treatment goal of bringing down her numbers by resorting to insulin.

'The goal is to avoid insulin'

In the following consultation, 81-year-old Edward had come to see his doctor, David about his diabetes. Edward had had diabetes for about a year. He had only recently started medical treatment. In this part of the consultation David and Edward talk about how they can bring down his high blood sugars even though he is taking metformin.

David:	What will happen over time is, if we don't get on the behavioural part of this thing, we will have to give you more medicine. We'll have to increase the dose of the metformin, and then we'll have to give you another medicine. Eventually over time it will lead to some type of injectable, and it is important for you to be aware of that.
Edward:	Which means what?
David:	Which means you'll have to administer an injection to yourself.
Edward:	Oh boy, that's like insulin?
David:	Not necessarily, and that's something for you to know today. That the progression of the disease can be slowed by behaviour, that's number one. Number two, as in any chronic disease we have to keep up with that so to the extent that your body is not able to compensate, we have to add more medicine. So we have many different things we can add to you. But what we like to do is add medicines that are not insulin before we get to the insulin stage. [...] The goal here is for the rest of your life to try to avoid the insulin and we should be able to do that. You'll do better. But if we have to go to insulin, then we will.
Edward:	I'm glad you brought up the phrase 'the rest of your life' you know I look at it; I'm 81 years old. I'm going downhill. And for someone in my age group to have this kind of diabetic condition seems to me like, er, passé [...] So I can't really understand, how I suddenly am susceptible to that kind of condition at my age-
David:	Well-

> Edward: And then the other part of that would be: who needs to get involved at this stage in my life to curtail that kind of condition? Because for what purpose almost? Because, who knows how long I have left? As they say…
>
> David: But nobody has a contract, Edward.
>
> Edward: Yeah I know, but that, that's why I feel like, you know, is it worthwhile to worry about it?
>
> [...]
>
> David: I think it's a very fair point, and I don't think it's an issue of worrying I think it’s an issue of being part of the team and that's a big difference.

In this consultation, David explained the progression of diabetes by the increase of medication needed. Like Jens, he presented the ‘behavioural part’ and medical interventions as alternatives, where the latter is increased if the former fails, and the goal thereby becomes ‘to avoid the insulin'. The treatment of diabetes is about reducing a future risk of complications, represented here as the risk of getting to ‘the insulin stage’. A premise of this logic is that progression and the risk of complications can be modified. As Cohn observes, temporal processes are fundamental to diabetes, and the notion of risk requires people to project themselves into a future in which they might suffer irreversible ailments, and act in the present to avoid such progress (2000:218). However, Edward’s reaction made for another way of relating to the future. When he projected himself into the future, he did not imagine avoidable damage, but ‘going downhill’ and not knowing ‘how long [he] had left’.

At the beginning of this chapter, I observed that the medical model, like the ‘user journey’ discussed in chapter two, holds an assumption about temporal sequence of events, where diagnosis is followed by treatment leading to improved health. The two treatment technologies, however, belong to different temporal configurations. In diabetes care, the present moment is about pre-empting future complications as well as increased treatment. The future is already present with the picturing of possible future outcomes of current efforts or shortcomings. In hearing care, the present moment is an evaluation of the body’s current functionality. The impairment needs to be a ‘big’ problem, as Sebastian observed. He therefore encouraged Svend to go home and think about his need for treatment, and come back when he believed it had gotten worse. The future is not pre-empted but awaited. In hearing care the ‘bad conscience’ that the hearing aid may become is avoided by postponing the onset of treatment; in diabetes care the obligation, and potential bad conscience, is brought in as an argument for making an effort or ‘being part of the team’ as David said and bring the blood sugar down to ‘where they *must* be’ as Jens observed.

In the following interaction, the blood sugar numbers are fine, and insulin is brought up circumspectly. Matt has recently been diagnosed with diabetes. He is now in for his review with the nurse practitioner, Karen. They start out the consultation by going over his blood work:

Karen: Alright so we’re gonna go through your blood work now, and everything looks pretty darn good. There’s a little elevation in the lever enzymes, but that’s fatty lever, so once we get rid of some of this (*Karen points to Matt’s belly*) Have you been exercising?

Matt: Erm... Yeah at work, ha.

Karen: Okay, Matt, extra! So if we can get a little bit extra with that then, erm, that's gonna go down. But I mean you're doing a lot better from when I saw you the first time. Alright, that's the one thing. The HbA1c is on the money. Okay, so I don't want it any higher than 6.5, but 6.5 means you're under control.

Karen explains the meaning of HbA1c. They talk about his current medication and about eating habits

Karen: Do you have any questions or anything? Did you want to do anything different?

Matt: Yeah I wanted to lose weight.

Karen: You want to try Victoza[3]?

Matt: Anything. As long as I lose the weight. I think, if I lose the weight, I would feel much better.

Karen: Yeah. I can add a little Victoza to your regimen. That's a needle. Would you try it?

Matt: It's a needle?

Karen: It's kind of like-

Matt: I'm not scared of needles.

Karen: Okay it's kind of like the one that Monica does. You know, how she uses it for the insulin? But this is different, it's an-

Monica is Matt’s wife. She has type 2 diabetes and gets insulin.

Matt: Oh, it's an insulin?

Karen: It's NOT an insulin.

Matt: Ohhh.

Karen: It's not an insulin. What it is, it's like a- it's like an insulin, but it's gonna synthesize the cell and it's gonna help you absorb the sugar better.

Matt: I know, I have to give that to myself?

Karen: Yeah, once in a while.

Matt: Yeah, yeah.

Karen: You wanna try it here?

Matt: Ah, no! I hate needles.

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[3] Victoza is produced by Novo Nordisk and is an injectable antidiabetic from the drug group GLP1. Unlike insulin, it does not cause weight gain, but may contribute to weight loss (Novo Nordisk 2014d).

Karen: Ha, ha, ha. Now you hate them?

Matt: I've seen my wife doing it and it's like…

Karen: No, it's not so bad.

Matt: I like to give it, but not receive it, ha.

Karen: Well you can give it to her and she can give it to you. But it's only once a day; it's not like hers. It's completely different. It's not an insulin- it's, it's more so, it's gonna to make your cells more sensitive so that your sugars are gonna be better. I mean your sugars are good now that's why I'm like - it's totally up to you.

Karen explains that Victoza will make him feel full for longer and maybe nauseous too, which will cause him to lose weight. She brings out the device to show him, and he agrees to try it out at home.

In this consultation, the blood sugar test was ‘on the money’, which Karen translated to Matt as being ‘under control’. This controlled stage allowed them to turn diabetes care from treating numbers to engage in Matt’s wish of losing weight and his hope that it will make him feel better. These were the two points that Olga made in her own consultation; she was feeling fine and was losing weight, but that receded into the background as her numbers were too high. Insulin lowers the blood sugar, and together with the measuring technology it strengthens the focus on numbers. For both Olga and Edward, the behavioural effort is figured as an alternative to increased medication and hence made out to be the cause of their numbers. For Matt, however, the numbers are fine and relate differently to the causality between his lifestyle and diabetes. His treatment goal is to lose weight. Matt is committed to this goal and is even willing to inject himself, until Karen mentions that the needle is of the same kind as the one his wife uses for insulin. He then uses the needle to explain why he wants to reject the treatment. Karen reacts with surprise: ‘Now you hate them?’, indicating that his resistance relates to something other than the needle. It makes for an interesting observation in relation to the concept of barriers. The literature suggests that ‘fear of the needle’ and the difficulty of administering injections at home are amongst the concerns that keep patients from starting insulin treatment (Larkin et al. 2008). In this interaction, Matt dismisses fear of the needle, but then uses it to account for his resistance to the insulin treatment. It shows that what we usually term ‘barriers’ gain meaning from their use. It suggests that barriers elicited from self-administered questionnaires and surveys, as in the study by Larkin and colleagues, may say as much about shared cultural perceptions of the treatment technologies, as they do about what actually keeps people from starting treatment. I will unfold this observation when I discuss motives and situated actions. First I will demonstrate the indeterminacy of insulin as a solution to the problem of diabetes with a deviant case.

‘If you feel more comfortable on insulin, we can leave you on it’

What these situations share is that patients view insulin as a treatment that is radically different from other treatments for diabetes; the use of insulin implies that the diabetes has progressed and that previous efforts have failed. Maybe some of these observations were the why Karen later introduced insulin to another patient in a very different manner. In the following Karen and Pedro (introduced in chapter three) are talking about how they can bring down Pedro’s blood sugar:

Karen: Well this is the thing. I want to do just a little adjustment. M’kay, so I only have you on Onglyza[4], but I want to put you on two medications.

Pedro: Mhm.

Karen: Okay, but I'll make it a combination pill, so it'll be easier.

Pedro: Okay.

Karen: Okay, and I have samples, so I can sample you out. So you did this, er, you did your blood work in October. November, December, January. January we're gonna recheck it again. I know your HbA1c is going to go down, but right now it's so high that, erm, if it's not lower than nine then I might put you on insulin. Like a basal dose[5].

Pedro: Mhm.

Karen: Just for the fact that it'll control your sugars a little bit better.

Pedro: Okay.

Karen: And then once we get you under control, I can take you off of it, or if you feel more comfortable on that, we can just leave you on the insulin.

Pedro: Okay.

Karen: Alright. Okay, but let me get some samples for you and let me take a look at everything.

They discuss his blood pressure, cholesterol, exercising and smoking, and make separate plans for these issues.

In this consultation, Karen presented insulin as a fairly unproblematic and temporary means to bring down the blood sugar value. Pedro’s well-being was part of the treatment goal, as the length of time he will be on insulin depends on how comfortable he is with the treatment. In this consultation, insulin does not mark a radical change. The high numbers are not made out to be the consequence of failed efforts to treat diabetes, and numbers and lifestyle issues are treated as separate problems. Only after the discussion on anti-diabetics did Karen address Pedro’s weight

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[4] Onglyza is an oral anti diabetic that increases the release of insulin; it is often used in combination with metformin (AstraZeneca 2013).

[5] A basal dosis of insulin is a long-acting insulin, usually injected once or twice a day. When there is need for a closer regulation of the blood sugar, a fast acting insulin will be added, which is taken before meals (Novo Nordisk 2014b)

and his habits of smoking and exercise as separate issues. Diabetes care was framed in terms of treating several problems, where insulin is the solution to just one of them, and matters of weight-loss and healthy living have nothing to do with blood sugar values.

I opened this section by suggesting that treatment technologies do not simply solve health issues. They may have the capacity to transform disease to a solvable problem but may also set a trap as they require extensive work on the part of the patient and directs attention to particular aspects of the disease problem. The consultations above show that hearing aids and insulin are designed to solve specific aspects of hearing loss and diabetes, and thereby represent particular and partial figures of the conditions. The hearing aid represents hearing impairment as a sensory impairment and a matter of sound levels and qualities. Insulin treats blood sugar values, and addresses diabetes care as a matter of numbers that are too high, most often a situation where the patient has not arrived at 'the behavioural part' of diabetes treatment, and medication has to be increased.

The diversity of consultations, however also demonstrates that patients see these technologies in different ways. When an audiologist suggests several combined solutions to hearing loss it represents a more complex picture of the impairment, including not only the lost sounds but also the possible difficulty of asking other people for assistance. Karen uses a variety of solutions in Pedro's diabetes care so that the high number is just one component of his diabetes and not the result of all his efforts.

MOTIVES AND SITUATED ACTION

To understand the relation between the medical conditions and the treatment technologies, I have attended to 'moments of treatment', in which devices are introduced as possible solutions. In this section, I will discuss the differences between my concern for 'moments of treatment' and the interest in moments of 'initiation' of insulin and 'purchase and fitting' of hearing aids that were outspoken in the companies. In the companies, these moments received special attention, as they marked the onset of treatment with the companies' products. Mol describes this reasoning as *logic of choice*, where patients are depicted as individuals who make choices about treatment and much like the medical model depicted above, it follows a linear temporality, where choice is followed by implementation of treatment (2008). The logic of choice entails that patients are provided information by their clinicians so that they can make their own choices. The moment of choice is embedded in a sequence of fact-choice-action, where clinicians provide the facts in form of diagnosis and availability of treatment options, while patients form their own opinion before choosing a treatment, which is then implemented (ibid.).

This idea that people treatment choice originates from an informed, educated individual who decides that it is the right moment to start treatment was also present in the representations of potential users amongst my colleagues in the companies. When Janet and I presented our project, a colleague working on patient research in Novo Nordisk commented that the most relevant people to address were patients who were eligible to use insulin, meaning people who were in a position to benefit medically from taking insulin. The challenge was then, he explained, to give them an 'appropriate understanding of the disease'; when treatment can no longer be postponed the patient should be addressed in an 'effective educational way' to build confidence that the condition can and needs to be treated. From this stance, it was not about barriers, he said, but about motivation. People needed to see that they must take charge and bring the condition under control. They should be supported in setting a reachable goal.

In Oticon, I encountered a slightly different approach. In 'New Insights into First-time Users', Schum and colleagues set out to understand what prevents potential users from seeking treatment (2012). They observe that the only factor that predicts whether a patient will seek out and obtain treatment is 'self-reported hearing difficulty' (ibid:7). They argue that health care professionals should instil a sense of motivation and readiness in their patients. Their targets are not people who can no longer postpone treatment, as in Novo Nordisk, but patients who 'show some level of interest in obtaining amplification' and who express the need and desire for treatment (ibid:13). From here, however, there is an equal amount of attention to stimulating the desire for treatment. Schum and colleagues argue that professionals must understand the 'mindset of the potential hearing device user' to achieve a more positive outcome (ibid:3).

Whether the focus is on barriers, motivation, interests or needs it portrays a person who makes choices about treatment based on personal conviction. Health care professionals offer education, information and understanding to prepare their patients to make informed choices. In this representation of clinical interaction and treatment, the capacity to choose and act is inherent in the individual. Patients are seen as motivated individuals who make choices and then follow them with action. I argue that this way of conceptualizing the prospect of treatment is an oversimplification. Scrutinising the entanglement of problems and solutions, we see that the onset of treatment cannot be reduced to a matter of choice by made by an individual actor. If we take an interactional stance, treatability is a practical accomplishment, and patients are not primarily subjects who make choices. The way we relate to each other as subjects, with epistemic authorities or behavioural right and obligations, are intersubjective productions emerging from interactions between doctors, patients, measuring devices and treatment technologies.

In his work on human conduct, Dewey argues that when we describe motives as the reason for actions, it is because we seek to change actions: 'The whole concept of motives is in truth extra-psychological. It is an outcome of the attempt of men to influence human action, first that of others, then of a man to influence his own behaviour' (Dewey 2003:248). The conceptualization of a motive – or barrier – is part of the attempt to direct action in a particular way; it is consolidated with preferable ways of dealing with a situation. Dewey develops the consequences of this stance and argues that 'a motive does not exist prior to an act and produce it. It is an act plus a judgment upon some element of it, the judgment being made in the light of the consequences of the act' (Dewey 2003:248). In this way, he depicts subjects as primarily acting, while accounts for the motives that are subsequently produced. These stories bring together certain events in an evaluation of their consequences. If we take Dewey's advice, and see things in their complex entanglements, human action does not figure as separate entities such as choices followed by action. It may better be described with what Suchman terms 'situated action': 'actions taken in the context of particular, concrete circumstances' (2007:26). She argues that human action is best described in these terms 'because the circumstances of our actions are never fully anticipated and are continuously changing around us' (ibid.). When we produce accounts that make our actions appear planned, it 'says more about the nature of our analyses than it does about our situated actions' (ibid:72-3). When potential users are depicted as individuals who choose their treatment based on motivation and interests, we may see it as a selective analysis guided by the interest in expediting the access to treatment. As any analysis, it is partial, interested and selective. With my attendance at 'moments of treatment', I want to bring forward some of the aspects that are left out, when the capacity to act is located in a choosing individual. In contrast to the logic of choice, *the logic of care* attends to the patient's practical engagement with handling his or her condition. In this approach people take part in a multitude of activities, including examinations, treatments and daily life with a chronic condition, not only by choosing, just like I have depicted the people I met during fieldwork. The focus is not on patients' will, but on their actions. In this logic, there is not one moment of treatment choice, but rather an interactive, open-ended process. In contrast to the individual patient who chooses treatment, Mol introduces 'doctoring' as a shared activity in which patient and clinician experiment with different solutions. She observes that:

> Care practices tend not to be linear at all. Facts do not precede decisions and activities, but depend on what is hoped for and on what can be done. Deciding to do something is rarely enough to actually achieve it. And techniques do more than just serve their function – they have an array of effects, some of which are unexpected. Thus, caring is a question of 'doctoring': of tinkering with bodies, technologies and knowledge – and with people, too (Mol 2008:12)

This approach reminds us that moments of treatment are situated in a process of care, and even when deciding to start treatment, it takes much more to get there. Per, who I visited in his home had been fitted with hearing aids by his audiologist, and described the change in his hearing as he was driving home from the clinic: 'There was no doubt that I heard better, that sounds around me were easier to hear, or higher than they used to be [...] the mat on the car floor was lose, and when my foot came across it, it would make a sound, and I suddenly heard that sound a lot of times, and that actually irritated me'. Upon arriving at his summer home, he worked in the garden as he ordinarily did, but found the noise of the hedge trimmer unbearable, he told me. For this reason, he said, and because he did no need to talk to anyone as he was gardening, he stopped wearing the aid, when he was in the garden. After a few months he returned the hearing aids. When I met him, a few years had passed and his hearing had deteriorated. He wanted to try another clinic and another aid. What we may depict as his initial motivation and consequential decision about obtaining amplification was not followed by onset of use, but led to other problems and changes in his circumstances.

In the consultation with Olga, a list of 'barriers' was brought up, including dependency, difficulty of the routine, and restrictions on her life. Jens inquired into these by asking if they were that bad, to which she replied that she did not know because she had not tried them, implying that her concerns were not based on a familiarity with the device, but were rather an expression of uncertainty. When I met Olga a few months later, she had started daily injections of GLP1[6]. She had learned to inject, her numbers were well regulated and she told me that she was happy with her treatment. It was no longer relevant for her to decide if she wanted to use insulin, and what at first appeared to be an inevitable decision ceased to be relevant. In both situations, the sequential temporality in the logic of choice had disintegrated. Mol observes that in the logic of care it does not make any sense 'to put arrows between events and order them in a linear manner' (ibid:54). There is no unfolding of temporal sequences of events. In the logic of care, time folds, she argues, as future hopes are brought into the present, while the past is present in the ineradicable traces it has left.

Attending to the primacy of interaction, temporality emerges with practices of dealing with the medical conditions. I have observed that the future is attended to differently in caring for diabetes and hearing loss. In diabetes care, the future is already present as people are required to project themselves into a scenario of possible future complications. The treatment builds on a pre-emption of future disease. In hearing care, the present moment is a matter of evaluating the impairment, and there is rarely any pre-emption of future complications. The future is awaited until the hearing impairment evolves into what Sebastian called a 'big problem'. As situations

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[6] GLP1 is a self-administered injectable anti-diabetic, most often used one or twice per day.

change, so might the outlook on the future, as it did with Olga and Per. Doctors and patients deal with health care issues and changing circumstances. In this process, 'moments of treatment' figure as instances of interactions between doctors, patients, bodies, measurements and treatments, not as pristine moments followed by a sequence of events. They are granted attention, because we learn about the enmeshment of disease problems and their medical treatments. At the same time, patients and doctors are depicted as active participants, who inquire into and deal with problematic situations.

CONCLUSION

I have dedicated this chapter to an examination of the treatment-technologies-in-practices. My analysis shows that specific representations of health care problems are committed to particular kinds of interventions. With the analytical strategy of exploring how medical conditions are configured in relations to the technologies, I have shown that hearing aids and insulin are associated with particular assumptions about the problems of hearing impairment and diabetes. With hearing aids, hearing impairment is configured as a sensory experience felt by the impaired person. This person needs to have a measurable loss and feel sufficiently bothered or inconvenienced by hearing difficulties to want treatment. The aid offers a solution in the form of amplification, but also requires a commitment not to leave the aid in a drawer where it becomes what Anna calls a 'bad conscience' With insulin, diabetes is configured as a matter of high blood sugar, and the treatment goal is to bring high numbers down. Insulin has the capacity of regulating elevated blood sugars, and in this configuration, other potential treatment goals as losing weight or feeling well, may temporarily fade in the background. Insulin is often considered the last step on the treatment ladder and progression of the disease is depicted as the consequence of other attempts failing to treat the condition. When doctors and patients inquire into the need of treatment, it is a matter of (mis-)aligning a specific problem of diabetes or hearing loss with the problem represented by the treatment technologies. As I attend to technologies-in-practice across situations, it also becomes clear that technologies do not determine disease categories, but are related to in different ways, as when Sebastian tells Svend that it is optional to wear a hearing aid once it is acquired or Karen tells Matt that he can stay on insulin if he feels comfortable with it. The enmeshment of disease problems and technological solutions is a matter of situated interactions.

In the medical model, the patient is an experiencing subject who notices symptoms, while doctors examine the body and identify signs. Attending to the interactional work of producing (non)treatable conditions, capacities and obligations to know the medical condition and act upon it emerge within relations to the technologies. In the ‘moment of treatment’, the patient suffering from hearing impairment has epistemic authority to know her capacity to hear and to evaluate the amount of problems it causes. This subject position differs considerably from the position in the home, where it may be difficult for the impaired to argue his or her case, since it is hard to know what was not heard, as Stephan observed. In the clinical encounter, there is often no sharp distinction between the sensory experience of hearing difficulties and personal judgment of the extent of problems it causes. The patient is ascribed authority to know her hearing, and the decision about treatment, as George told Allen, is an ‘obviously personal decision’. The subject position that emerges from relating to insulin in diabetes care comes with different rights and obligations. The treatment goal of lowering blood sugars and preventing complications is difficult to reject, and the patient’s experience of well-being matters little when the numbers are too high. There is instead an obligation to be what David terms ‘part of the team’ and get the numbers ‘where they must be’ in Jens’ words. Attending to the primacy of interaction, subjectivity emerges from relations between humans and technologies.

In my analysis, human action unfolds in particular and changeable circumstances; the capacity to act not is inherent in an individual driven by motives or barriers. Nonetheless, I did come across negative expectations about the treatment devices, as hearing aids were associated with old age and infirmity and insulin was associated with a more advanced stage of diabetes. Depicting these expectations as ‘barriers’, however, and seeing them as causes of actions, portrays people as subjects, whose motives for acting may be elicited from surveys independent of situated interactions. In the understanding I develop here, treatability is the result of relations, where subjects are not prime movers, but where rights and obligations to act emerge from relations to other people as well technologies.


"I think you are not paying attention when in fact you are just not hearing"
How is hearing loss made into a problem?
Hearing loss is not given, but created as a complex social problem in interactions.
"I think I just had a bad day, when you first diagnosed me..."

CHAPTER SIX

SITUATED REFRAMINGS

In this chapter, I consider a different social setting. In the previous chapters, I have shifted my focus from the clinical encounter to the homes to examine the diverse practices of handling hearing loss and diabetes. I have started from a primacy of interaction and observed that treatable conditions are not given, but locally configured in relations among the doctor, patients, tools and practices. In this chapter I return to the site from which my engagement in these issues originally emerged: the companies. I turn my attention to interactions among employees, our representations of ethnography and provocative design concepts. I explore the role ethnographic research may play in an industrial setting by analysing the immediate responses to the ethnographic material and design concepts we presented in the companies. I argue that our intervention instigated discussions about the problems of hearing loss and diabetes, and how they relate to the devices manufactured by the companies. Like the practices of relating and interpreting that are at play in the clinics and the homes, these discussions among employees, are matters of relating understandings of the medical conditions, the devices and its user in particular; they are matter of *situated reframings*. With this shift in the setting, my analytical concern is to understand, which assumptions and logics about users are at play in the companies.

The empirical ground for my analysis is an exhibition, which we arranged as a closing event of the project. The exhibition was accessible for three weeks, and was located at different sites in both companies. We offered guided tours and encouraged employees to leave their written comments as part of an ongoing a feedback stand. We introduced the exhibition, by suggesting that hearing aids and insulin are not only solutions to given health care problems, but also take part in constituting those problems. This idea was unfolded in the ethnographic material composed of stills and extracts from conversations recorded during fieldwork together with some open analytical questions. The purpose was to document and juxtapose different ways of relating to the conditions and treatments, thereby suggesting that the problems of the medical conditions vary across situations and are at the same time closely related to available solutions. The exhibition included eight provocative design concepts that suggested different ways of addressing the medical conditions and their treatments. The exhibition invited participants to see the conditions as configured in socio-material relations, and then suggested that since conditions are produced in relation to material objects, they might be reconfigured, or related to differently by changing the materiality that mediates the conditions.

In the first part of the chapter, I reflect upon our composition of the exhibition. By presenting ethnographic material for shared analysis and provocative design concepts, we intended to articulate some of the understandings underlying the design of hearing aids and insulin pens. The exhibition was open-ended. The ethnographic material was accompanied by a set of provocative questions, and not disclosed through one particular reading. By maintaining this ambiguity, we encouraged visitors to experiment their own readings of the ethnographic material. The design concepts were designed to embody some of the controversies we came across during our fieldwork, and the concepts I will focus on addressed two issues: the measuring of medical conditions and the invisibility of treatment technologies. With the critical design concepts we deliberately violated some of the commonly accepted norms about the conditions and their treatments.

In the second part of the chapter, I explore the immediate responses to the exhibited ethnographic material and design concepts. I argue that the exhibition opened up conversations about the diseases and their treatments, and caused rationalities about users and their motives and needs to be discussed. I also observe that visitors to the exhibition responded very differently to the material. We may best describe their reactions as ‘situated framings’; as a matter of connecting, contextualizing and interpreting the material. In concluding I therefore return to, what was the outset of the thesis, the ‘barriers to treatment’ stance, and observe that this model does not reflect the complexity and diversity in employees’ understanding and logics about their product and its potential users.

‘DO WE CREATE PROBLEMS OR SOLUTIONS?’

In the original framing of the project, the companies asked us to provide insights into the barriers that keep people from starting medical treatment with their devices. The intention was to learn how to expedite the transition to use. With the exhibition, our intention was not merely to respond to the companies’ curiosity about barriers to treatment. We wanted to address the assumption that people with diabetes or hearing loss suffer from a known medical *problem* to which the companies provide a *solution*. This approach accepts that ethnography may offer engineers and designers ‘not just detailed descriptions of […] daily life with which to fix the features of the design, but an opportunity to open up the overall problem-solution frame’ and ‘question the taken-for-granted assumptions embedded in the conventional problem-solution design framework’(Anderson 1994:170). When the companies consider hearing loss and diabetes to be problems that are solvable respectively with amplification technology and insulin therapy, it points to specific, yet partial features of the problems that the people with these conditions are dealing with. As I have demonstrated in the past chapters, the problems of diabetes and hearing loss extend far beyond the need for amplified sounds and tighter blood sugars regulation. With our ethnographic material, we wanted to open up the ‘problem-solution framework,’ by rendering visible the variety of problems people engage with and the ways they relate to treatment devices and other solutions. With the design concepts, we wanted to suggest different ways of relating to the conditions as well as the treatments.[1] The exhibition reflected three important aspects of our research: 1) the problems of hearing loss and diabetes are not ‘given’ singular entities, but differ from situation to situation, and emerge in a myriad of versions; 2) treatable conditions are configured in relations between humans and material, and the problem of a condition does not exist independently from its treatment, but is closely related to it; 3) since the conditions and the treatment technologies are made meaningful in relation to each other, they may be related to differently, or treatable conditions could be reconfigured by designing different technologies.

We introduced the exhibition by asking our visitors ‘Do we create problems or solutions?’ The text on the introductory stand continued: ‘Medical treatments, including devices and drugs, play an important part in defining how people understand what hearing loss and type 2 diabetes are. In our research we have found that both insulin treatment and hearing aids, are not simple solutions to an obvious problem for pre-users, but actually take part in creating the medical condition as a

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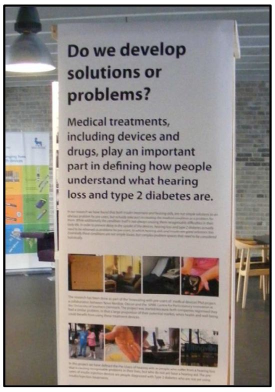
[1] As I will soon depict this ‘opening up’ not only as a contribution of ethnography *for* design, but a collaborative endeavor of anthropology and design, it is worth distinguishing between two notions of design. In his paper, Anderson refers to ‘design concerned with productivity’; which in our case means the design work conducted by engineers in the companies developing new devices. It is in this sense that our articulation of assumption is addressing the problem-solution framework of design. In the following, I will though refer to design in another sense; the critical and open-ended design work conducted as part of our research project.

TREATMENT

The Revealable Hearing Aid addresses the shared responsibility of communication by lighting up in situations with noise.

The Hearing Aid Coach can be used before and after fitting of hearing aids, and is a tool to learn to use hearing aids and reflect on the extent to which the aid helps.

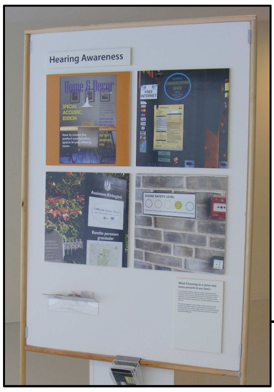
The introduction explained about the study and suggested that treatments not only solve but also impact the problems of diabetes and hearing loss.



HEARING LOSS

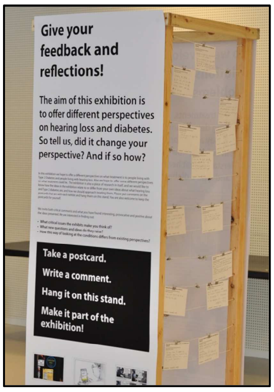
The hearing loss posters depicted extracts of two clinical encounters and part of a conversation between a hearing impaired man and his wife.

Hearing Awareness. A series of interventions designed to increase awareness of hearing, including a certification for sound quality in restaurants and cafés.



Shared Assessment is a two part concept that includes a tool for discussing hearing problems amongst family members and a list of advice on hearing techniques.

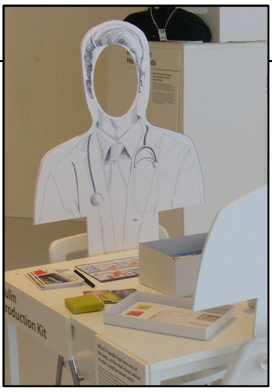
The feedback stand encouraged visitors to post written feedback as part of a asynchronous discussion.



Give your feedback and reflections!

The aim of this exhibition is to offer different perspectives on hearing loss and diabetes. So tell us, did it change your perspective? And if so how?

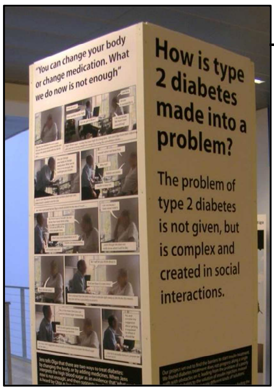
Take a postcard.
Write a comment.
Hang it on this stand.
Make it part of the exhibition!



Insulin introduction kit is designed to help health care professionals deal with some of the concerns about onset of insulin therapy.

The **Once daily device** is designed to be left standing out, and communicates simplicity of a routine that only involves once a day injection.

DIABETES



"You can change your body or change medication. What we do now is not enough"

How is type 2 diabetes made into a problem?

The problem of type 2 diabetes is not given, but is complex and created in social interactions.

The diabetes posters documented one occasion of reading a and making sense of a measurement and two instances of what I have called 'moments of treatment'.

***Act* on diabetes** works similarly to a blood glucose meter, but instead of displaying a number, it returns an advice on how to react to the blood sugar level.

The **Information Underload Service** breaks up the information about diabetes into manageable pieces and relates it to people's lives.

CONDITION

problem for them.' Our intent was to prod employees to reflect on the assumptions in the problem-solution framework, by suggesting that treatment devices also play a part in construction the disease problems. Next to the introductory stand were two columns with ethnographic material compiled from stills and conversations from recorded conversations between doctors and patients and between family members. Around the data stands, we had placed the eight design concepts. At every stand, the visitor could pick up a postcard, write down his or her comments and reflections and make them part of the exhibition by placing the postcard on the feedback stand.

By juxtaposing our ethnographic material and design concepts from both disease areas into a single shared exhibition, we wanted to pass on the analytical strategy of comparing the two chronic conditions and allowing contrasts between everyday practices of handling each chronic condition to render the each practice more visible.

Shared ethnographic material

We presented our ethnographic material on two square columns, one for each disease area. Each column showed three extracts of conversations from clinical encounters or the homes of our informants. In a cartoon format, we used stills and quotes from our recordings to make the presentation vivid and engaging. We placed moments from different settings and ways of relating to the conditions and devices next to each other, to suggest that there is a myriad of ways in which the diseases emerge as problematic for the people who live with them. The material spanned the clinical setting and the homes and represented practices of measuring, what I have called 'treatment moments' and conversations between partners who engaged in a shared analysis of the medical condition.

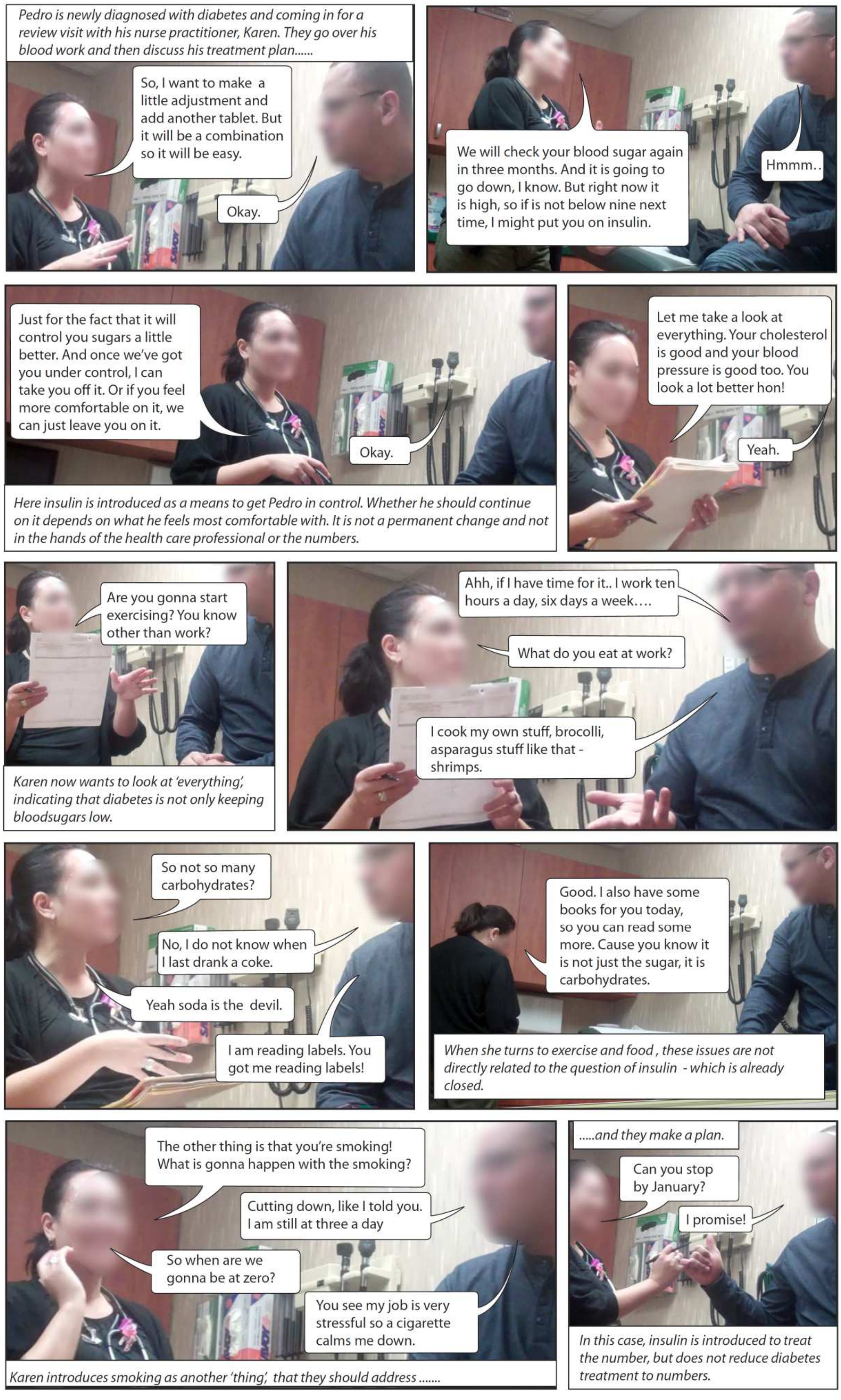
Underneath each interaction, we asked open analytical questions. The format of provisionally suggesting an analytical understanding of the ethnographic material, rather than spelling out *one* reading of the material, reflects the pragmatic understanding that meaning is always in the making. It was deliberately open-ended, to engage our visitors in making their own readings of the shared ethnographic material (Buur and Sitorus 2007). We did not translate or summarize our field experiences into coherent stories about the transition to use, or generalize the users' perspectives on diabetes and hearing loss or present typologies of barriers to treatment. We documented situated practices of locating, inquiring and solving problems, rather than our interpreted insights from the material. This may create the impression that we wanted to present ethnographic data in a 'raw' form, untouched by our practices for knowing. However, as I have pointed out, data are never 'given' but always 'taken' within a practice. That goes for our ethnographic material too; data emerge as part of a knowledge producing practice, or as Hastrup writes ‘we cannot speak of an anthropological object outside of a particular analysis. The object is a product of a particular epistemology, a way of knowing’ (Hastrup 2005:146). As much as the assembling of ethnographic material was intended to document situated interactions as they played out amongst our informants, it was also ‘taken’ from a particular analytical interest in foregrounding the locally unfolding relations among doctors, patients, measuring devices and treatment technologies. As Buur and Sitorus observe, using ethnography for employees to engage with, requires a delicate balance between maintaining an analytical perspective and ensuring sufficient precision on the one hand, while keeping an ambiguity that allows participants to ‘play with alternative readings’ of the material (2007:154) on the other. We sought to keep this balance by sharing our ethnographic material, while deliberately juxtaposing different ways of relating to the chronic conditions and their treatments and asking open-ended questions (examples are included in the second part of this chapter).

Provocative design concepts

The design collection consisted of eight concepts. Four of the design concepts addressed the medical treatments (upper row on the overview), and the other four addressed the chronic conditions (lower row). The concepts related to the medical treatment included provocative redesigns of the treatment technologies that render the devices much more visible than their current discreet designs (Revealable Hearing Aid and Once Daily Device), while another two are tools for introducing hearing aids and insulin injections to new users (Hearing Aid Coach and Insulin Introduction Kit). The designs relating to the conditions included two tools for alternative ways of assessing the conditions without producing numerical presentations as medical evidence (Shared Assessment and *Act* on Diabetes), a series of interventions to increase awareness of hearing (Hearing Awareness) and a tool for making information about diabetes simpler and more relevant to the patient (Information Underload).

The design concepts challenge existing perceptions rather than present readily useable objects. The approach was inspired by critical design methods, where artefacts are deliberately designed to provoke discussion by materializing controversies (Kelly 2014). The design work may be seen as a continuation of the sharing of ethnographic material, not in some direct progression from an ethnographic insight to a design solution – from description to prescription (Halse 2008), but in the sense that the ethnography rendered visible different ways of relating to the conditions and their treatments, while the design concepts suggested different ways of intervening in these relations.

‘I might put you on insulin, once we’ve got you under control, I can take you off it.’



I have argued that the representation of ethnographic material was deliberately left ambiguous so that visitors could play with their own interpretations. Using design concepts to open up the problem-solution framework poses a different challenge in this regard, since a designed tool does not have the same ambiguity and openness; it is an 'ultimate particular' as it addresses *one* problem to be solved (Stolterman in Otto & Smith 2013:3). The design of a concept is in a sense an analytical attainment that spells out one reading of the problem it is designed to solve.[1] However, by juxtaposing several designs that addressed the problems of the chronic conditions and possible solutions in different ways, we suggest that there is a multitude of possible solutions to these problems. Each design concept addressed different mediations of the condition or the treatment, and the exhibition as a whole critically explored the role of devices in the emergence of treatable conditions. The ethnographic material and design concepts together were intended to provoke conversations and reflections on current and possible relations among people, technologies and practices.

The exhibition was set up in open and easily accessible areas at the headquarters, first at Oticon and then at Novo Nordisk. We arranged an opening event the first day of the exhibition and had invited representatives from both companies for guided tours, where Janet and I presented our work. Among the visitors were employees from corporate strategy, user understanding, research and development, and marketing. During the tour we encouraged participants to discuss the work with us, and to leave comments on the feedback stand as part of the exhibition. Over the three weeks that the exhibition lasted, 73 cards were filled in, most of them during the opening tours.

LOCATING PROBLEMS, REFRAMING SOLUTIONS

As we were setting up the exhibition stands in the opening hall of the headquarters at Novo Nordisk, people topped up and asked about our work or commented on the exhibits. I remember one particular occasion where a person from consumer insights in Novo Nordisk asked me what we had discovered with regards to new reasons why people do not start treatment. I explained that the message of our project was to change the question and not search for reasons why people do not adhere to rational of use medicines, but inquire the situated and emerging relations between chronic health problems and medical treatment devices. He did not seem convinced about this shift of approach to potential users, and the conversation made me concerned that people would

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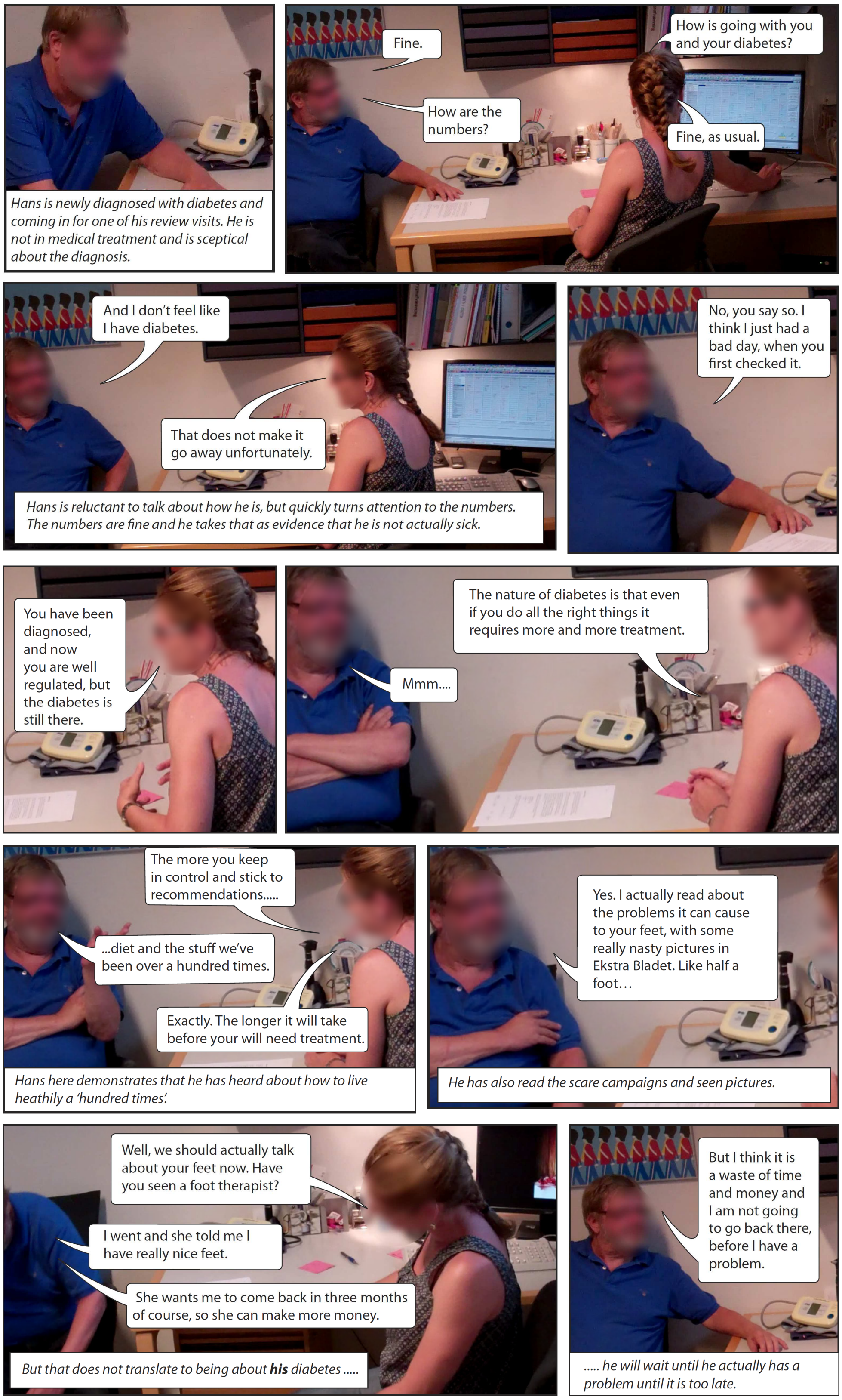
[1] In the field of design, it has been observed that design is never faced with pre-existing problems to be solved through design, but rather ill-defined or 'wicked problems,' as a result of which design is not merely a problem *solving* engagement, but a problem *defining* task (Buchanan 1992).

‘I think I just had a bad day, when you first diagnosed me...’



read the exhibition as having missed the core question: why do pre-users not start treatment earlier? Part of our provocative approach was to situate this individual in a context of relations, rather than focusing on that individual selecting a treatment. A related concern was if our work would contribute a new understanding of the pre-users, or of it would be old news. Based on our visitors' reactions, these were relevant concerns. In their comments, some people mentioned that patients needed to accept their condition and the need for treatment, picturing the onset of treatment as a matter of individual choice. Other visitors pointed out that the fieldwork had not changed their perspective. However, some people engaged differently with our relational approach. In the words of one employee: 'I find it very interesting to look at the complexity of the problem and the relatedness to social interaction. We are in business still struggling with how to address social interaction via devices.' Most interesting was the diversity of the feedback that shows how the ethnographic material and design concepts were contextualized and reacted to from a myriad of positions. Whether or not visitors believed that our exhibition brought a new angle to the relation between the problem of chronic conditions and their treatments, the visitors engaged in locating, what to them were the problems of the conditions and then reframed their products as solutions. In the process they expressed their assumptions about users, medical conditions and treatment devices that were at stake in the companies.

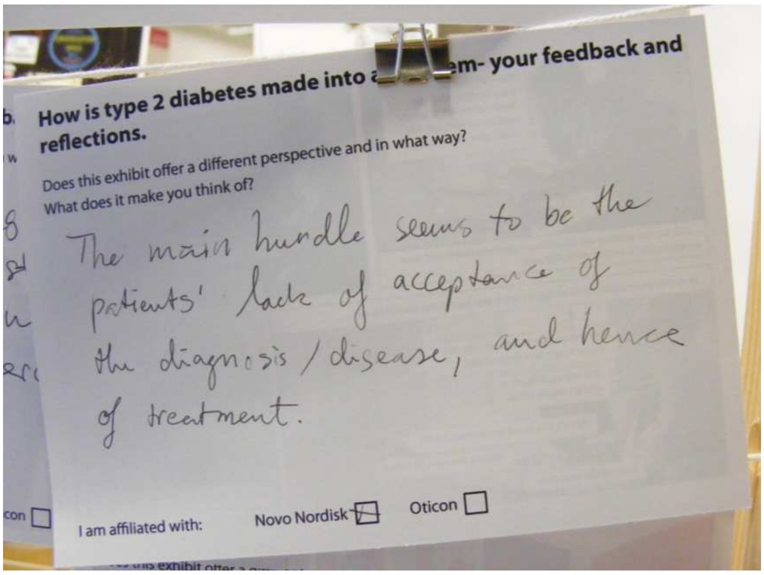
Locating 'the problem'

In many of their written comments about the ethnographic material, people engaged in identifying the problem in clinical interaction. In reaction to the stands with clinical encounters about diabetes (see page 170, 172 and 176), one participant commented: 'The main hurdle seems to be the patient's lack of acceptance of the diagnosis/ disease and hence of treatment'. In this reading of the ethnographic material, patients need to be brought to a point of acceptance, where they realize the need for treatment. In another comment the potential for action was placed on the doctor: 'I see the point of decision making as critical. Putting it off is apparently normal and natural – but has serious consequences. Doctors need a tool for explaining consequences of waiting, and benefit of starting treatment.' In this comment, attention is on the point of decision making, consistent with the focus on 'treatment initiation' and 'purchase and fitting' as moments of crucial importance with consequences for a following sequence of events. In this reading, the doctor is responsible for putting off the decision, which resonates with the responsibility put on the professional for nurturing 'readiness' for treatment, as I observed in the past chapter. Another participant suggested that health care professionals should relate differently to their patients, and understand them better: 'The case very well instances the typical clinical situation. What is important is for the diabetes nurse/doctor to understand what is going on in the mind of the patient: being unable to cope with/comprehend the situation.' In this comment, the doctor is urged to understand what is going on ‘in the mind’ of the patient, who does not comprehend his own medical situation. In many instances, the ethnographic material elicited comments about the relation between the doctor and the patient and how it might be altered. It articulated a general concern for ‘decision makings’ and bringing the patients to accept and comprehend the seriousness of their medical condition; doctors should listen to and understand their each patient’s perspective and make the need for treatment relevant. These comments articulated the understanding that action originates from motivation, and that health care professionals should be understanding as they educate and support their patients in making the right treatment choices.

These brief comments reveal assumptions about users within the organizations and reflect the concern for rendering people aware of their medical condition and of the need for starting treatment. On an earlier occasion, we talked to a leading researcher on professional relations in Oticon, who advocated a more patient-centred approach to the delayed onset of treatment. He said that hearing care often is not individualized enough; it should take into consideration that people are in very different situations, when they are introduced to hearing aids; some are ready to start treatment, while others ‘have not had that conversation with themselves.’ The core problem of hearing impairment, as he saw it, is that it makes the patient withdraw and become less active. That can potentially influence that patient’s health and can even lead to depression, he said. When a person’s health deteriorates, he or she interacts less. ‘The better they stay connected, the better their health,’ he reasoned. Patients may not see it that way, he said, but the professional does. He argued that hearing care is about the provision of holistic care. In other words, the hearing care professional understands the patient’s perspective, but also makes the patient aware of the health issues that can arise from hearing loss.

I met a similar line of argumentation in Novo Nordisk, where a leading researcher on patient needs and attitudes told us that when patients acquire an ‘appropriate understanding’ of their condition and realize that complications are preventable, they are more likely to take responsibility for their treatment. Like the request for an individualized approach from the specialist in Oticon, he argued that diabetes care should be attentive to the capabilities of the patient. He was concerned about finding a positive drive for people to use whatever resources they have.

These approaches to hearing loss and diabetes reflected a shared reasoning about the problem of chronic conditions; when armed with information and motivation, patients will take action. If the diabetes patient gains an ‘appropriate understanding’ of the risk of complications of diabetes, and the hearing-impaired person comes to see the relation between hearing loss, isolation,



How is type 2 diabetes made into a m- your feedback and reflections.

Does this exhibit offer a different perspective and in what way?
What does it make you think of?

The main hurdle seems to be the patients' lack of acceptance of the diagnosis / disease, and hence of treatment.

I am affiliated with: Novo Nordisk ☒ Oticon ☐

A postcard from the stand with ethnographic material, with the text: 'The main hurdle seems to be the patients' lack of acceptance of the diagnosis/disease, and hence of treatment.'

depression and poor health, they will be motivated to act. As Cohn points out, this understanding of risk is closely related to a rational model of human behavior: that individuals act on basis of calculated risks (2000). The approach is part of a process of individualization that places the ability to know and act upon disease on individuals instead of groups (ibid.).

The problems of hearing loss and diabetes were here articulated as a discrepancy between the real health risk of the conditions, and patients' beliefs about their health that caused them to act irrationally. From here, a solution is that health care professionals, supported by the companies who may develop tools for communication, educate and inform their patients about health risks, support them in gaining the right understanding and in making good choices.

Considering 'motivation'

In one of our guided tours through the exhibition, employees discussed the creation of motivation and readiness for treatment. During the tour, I introduced the two data stands, and suggested that the relevance of treatment is not given, but an accomplishment of interactions. I pointed out that the treatment itself plays a part in this interaction; when a treatment is taken into consideration it will foreground some but not all aspects of the condition. I gave the details of two cases. The first 'treatment moment' came from the conversation between Olga and Jens (see page 176). In the dialogue displayed, Jens and Olga evaluate past efforts to treat the diabetes and Jens introduces insulin as the next option for bringing the blood sugar down to the normal range.

’You can change your body, or change medication. What we do now is not enough’

Below the dialogue, we asked our visitors some questions that I read to them during the introduction: ‘When insulin is made the solution to the problem that ‘what we do is not enough,’ are other efforts turned into failures?’ and ‘With the extensive focus on blood sugar level as treatment goal in this consultation, is diabetes care only about blood sugars, while hiding other essential aspects of diabetes?’ The dialogue was juxtaposed with the consultation in which Karen introduced Pedro to insulin as a temporary means of lowering blood sugars, to show that the solution does not determine a particular problem, even if it does impact it. From the hearing loss data stand, I went over an extract from the consultation with Svend and Sebastian (see page 178), where they go over the test result and Sebastian tells Svend that whether he needs hearing aids depends on his own experience of the problems his impairment causes. One of the open analytical questions was: ‘When a hearing problem is not annoying to the patient, is it even a hearing problem?’ pointing to the relation between the ability to hear and the personal perception that the impairment is bothersome.

As I had completed the introduction of the stands, Camilla, from marketing and development of tools and services for health care professionals in Oticon, addressed the apparent absence of ‘a burning platform’ to mandate the treatment. Mads, from Concept and innovation facilitation in Novo Nordisk questioned her conclusions:

Camilla: I think that what they both [the two consultations with Jens and Olga and Sebastian and Svend] are missing is a burning platform; that they *need* to do something. You can have problems, but if the problems are not that big that you want to do something, you are not motivated. So to some extent, it is not missing because they did not do it, but maybe, that kind of creating a burning personal platform. Why should you do something tomorrow if there is not a need for it? Even though you have a problem, and you can have problems, I have many problems, but I do not solve all of them – some of them I solve because they are *crucial* to me.

Ditte: So, what you are missing is that in the doctor's approach to it?

Camilla: Yeah, creating that burning platform, or making it like: I have a *need* for a change.

Mads: The diabetes doctor [Jens] does stage a burning platform.

Camilla: Yeah but he does not have the patient on that platform -- he creates one, but she [Olga] is not on that burning platform, she is like ’yeah right.’ I think there is a big difference between creating it, and the patient creating it for herself.

Mads: The hearing loss doctor [Sebastian] is asking for the burning platform –

Camilla: Yes he asks for him [Svend] to maybe create that burning platform. He could push it even further […] he could ask even more questions to the patient to make the patient create his own burning platform.

’You must feel you have problems, or the hearing aids will end up in the drawer.’

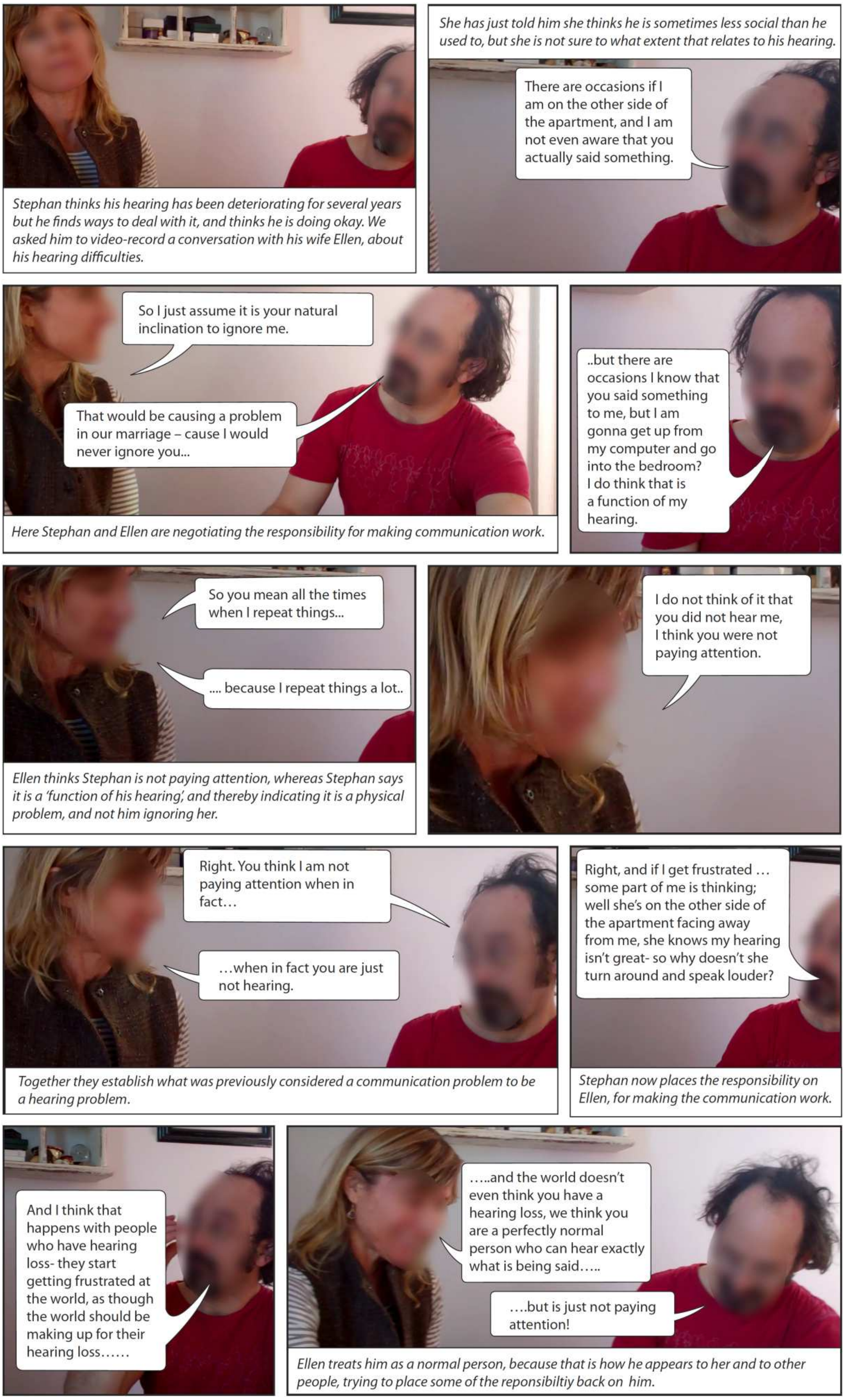
Per: We are not looking for the ENT [ear, nose and throat doctor] to create a burning platform. We are actually looking for the patient or the client to *realize* some burning platform; that is a different thing.

Camilla engaged in analyzing the relation between problems and solutions. While I had suggested that available solutions affect the way in which problems are articulated, she identified another connection between problems and treatments: the transformation of a problem to a solvable problem requires 'a burning personal platform.' As Buur and Sitorus observe, the ambiguity of ethnography as 'shared material' allows employees to 'play with alternative readings' (Buur and Sitorus 207:154). In Camilla's reading of the ethnographic material, the concern was not how the problem of hearing loss or diabetes is shaped by the treatment technologies. She was working from the premise that problems, such as hearing loss, preceded the practice of rendering them visible, while the challenge is to make the medical condition of crucial importance to the patient. In this reading, making treatment relevant is a matter of bringing the patient to a burning platform.

The participants in the conversation agreed on the need for this platform, but Mads and Camilla expressed different attitudes to the doctors' roles in creating it. As Mack and colleagues observe, sharing ethnographic material is likely to result in a 'clash of perspectives' as employees with different backgrounds and positions in the company relate in different ways to the material (2013:224). While Mads observed that the doctors in the interactions did were already doing enough, Camilla argued that the doctor could 'push it even further' and 'ask even more questions' to bring about the motivation for treatment. In reaction to this clash of perspectives, Per, who works in the same department as Camilla, claimed that it is not a matter of how much the doctor 'pushes' a patient. The doctor should not 'create' motivation; it should originate from the patient who comes to 'realize' the need for treatment. Per situated his argument in relation to the role of their organization, saying 'we [in Oticon] are not looking for doctors to create a need,' indicating a moral concern for not making up needs that patients do not recognize.

The open-ended format of the ethnographic material involves a particular way of relating to ethnography. In a corporate context, ethnographers are often consulted because they are 'suppliers of insight on the consumers of the enterprises' products' (Cefkin 2009:13). Their 'insights' gain validity from empirical field studies and from being informed by a broader frame than the commercial focus within the company. This allows the anthropologist to be insightful on 'situations of use, motivations, practices and sociocultural contexts' (ibid:12). With the exhibition we did not take a position as experts on user insights, and refrained from spelling out *one*

‘I think you are not paying attention when in fact you are just not hearing.’



Stephan thinks his hearing has been deteriorating for several years but he finds ways to deal with it, and thinks he is doing okay. We asked him to video-record a conversation with his wife Ellen, about his hearing difficulties.

She has just told him she thinks he is sometimes less social than he used to, but she is not sure to what extent that relates to his hearing.

Here Stephan and Ellen are negotiating the responsibility for making communication work.

Ellen thinks Stephan is not paying attention, whereas Stephan says it is a ‘function of his hearing,’ and thereby indicating it is a physical problem, and not him ignoring her.

Together they establish what was previously considered a communication problem to be a hearing problem.

Stephan now places the responsibility on Ellen, for making the communication work.

Ellen treats him as a normal person, because that is how he appears to her and to other people, trying to place some of the reponsibiltiy back on him.

particular reading of the empirical material (Buur and Sitorus 2007). The participants in the conversation above read the ethnographic material by interpreting interactions of doctors and patients, relating them to their understandings of treatment and connecting to their own role as manufacturers of treatment devices.

The shared ethnography instigated a consideration of motivation. The image of a 'burning personal platform' stimulated motivation as a necessity for treatment, and employees discussed the lengths that doctors should go to bring their patients onto the burning platform. This discussion produced a distinction between an externally created versus an internally realized need for treatment.

Rethinking the role of 'measurements'

In the exhibition we challenged the predominant role of measurements, and the ethnographic material we had selected showed ways in which people related to the numbers. In response to the hearing loss posters (see above), one person wrote: 'Very interesting discussion; what should be the determining factor: measurable loss or experienced problems? We know that lots of people with measurable loss do not know that they have a hearing loss = do not experience problems.' This reading took the issue about measurements to a more general discussion about how to address hearing loss from a company perspective, located in terms of measurable loss or in terms of experienced difficulties. For other people in Oticon, however, these questions were by no means new, and as I had finished my introduction of the ethnography, Per asked me if we had only focused on the clinical setting and ignored the home. I explained that we did both and showed him part of a dialogue between Stephan and his wife on the stand (see page 180). He then explained to me, as if speaking from the position of a hearing-impaired person:

> Per: To a very large extent it is not me, but my wife, who would say that I cannot hear. In other words, it is not *me*, who has to experience a problem it is as much the family. When we develop counselling tools, and that is mainly our responsibility, we have lots and lots of tools targeted at man and wife, that show how the situation is... I mean we *are* moving more and more away from measuring, and more and more towards counselling.

According to Per it was naïve to think that hearing impairment should be addressed as an individual and measurable problem. He contended that hearing loss is a family issue and should be treated accordingly, with couples counselling. In his understanding, numbers did not have a predominant role in hearing care, and Oticon was already active in the trend away from

The Shared Assessment is a two-part leaflet and includes a tool for family members to discuss their experience of hearing problems, and advices for communicating with a hearing-impaired person.

measurements. He did not only relocate the problem of hearing loss, but also reframed the solution as a matter of counselling, not only as one of amplification.

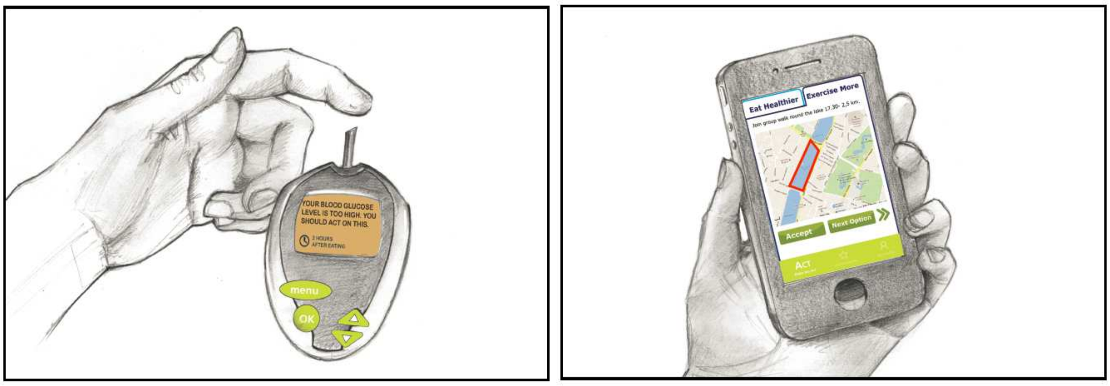
Another employee in Oticon wrote: ‘It makes me think of the inadequacy of audiometry – perhaps we should do other tests,’ indicating that what Per considered really old news was entirely new to this person within the organization. These two different reactions underline that newness is not so much a matter of radically new way of seeing something, but a matter of how people relate to an idea.

The critical design concept ‘Shared Assessment’ also stimulated the discussion about the role of measurements. During our guided tour, the concept was introduced with the argument that clinical measurements define hearing loss as an inability to hear discrete frequencies at certain sound levels. The Shared Assessment, by contrast, locates hearing problems in a social and relational context and is inspired by the mundane practices of assessing impairment we had come across during our fieldwork. The Shared Assessment is a two-part leaflet that treats hearing loss as a shared responsibility. On one side is an instrument for assessing hearing loss by situations that appear problematic to the hearing-impaired people and their communication partners. In an open ended question format it invites participants to bring up problematic situations, write down a corresponding keyword and place it on concentric circles that rank the problem from minor to serious. The idea is to engage family members in a collaborative inquiry into what makes these situations problematic and for whom. On the other side is advice on how best to communicate with someone who has hearing difficulties. Hearing difficulties are here addressed as a shared responsibility that may be worked around by changing distances, lighting and background noise.

An employee from Oticon observed that this assessment was not a new idea and took it as a starting point for discussing the possibilities and limits of treating hearing as a social problem: ‘This approach is for us [Oticon] not new, but can be relevant. I agree with the general concern that it is about making it a common communication problem, but may be difficult to deal with in daily practice/ home setting.’ While this comment suggests that Oticon should refrain from intervening in the home, another comment embraced the idea of moving to the home setting, but reflected on the limits of addressing hearing as a relationship problem: ‘Good thinking. We need to help people address this topic at home. Of course a lot of people hesitate to do so, most likely couples who cannot communicate with each other at all, but we cannot help that group :-) In healthy relationships, we will be able to bring the topic on the table and that is a good beginning.’ This comment makes it clear that even though hearing problems may be entangled with problems within the relationship, solving hearing problems is not about solving relational problems. While Per pointed to the need for locating the hearing problem in the home setting as a ‘family experience,’ this other participant explains the limits of this approach; hearing issues need to be set apart from other communication problems in personal relationships.

Although these comments treat hearing loss as *either* a measurable and individual impairment *or* an experienced and social condition, another participant observed that these are not opposite problems: ‘Hearing loss is both an individual and a social problem in communication, since both parts have responsibility. A hearing aid would help Stephan to be an equal part again.’ In this analysis of the conversation, the hearing aid is treated as a tool that repairs the individual problem, with consequences for the shared communication. There is no contrast between the physical impairment and the social communication problems.

For diabetes, the idea to *Act* on Diabetes suggested assessing diabetes by actions, and not by numbers. We introduced the concept by observing that blood sugar numbers may be the only indication of diabetes. At that same time, the number is also the only indication of how well people are controlling their condition; high blood sugar levels are often treated as a failed effort to comply with the treatment recommendations. In the shape of a blood glucose monitor, *Act* on Diabetes, measures blood sugars, but rather than returning an abstract number, it offers suggestions. The accompanying app records small achievements, by letting people request motivational prompts, then tracking when these are accepted. Users can set different types of goals and compete against themselves or use family members for support. *Act* on Diabetes



Act on Diabetes offers a way of assessing diabetes by action instead of by numbers.

suggests what might happen if measuring became a focus on what people do *do* to treat their condition, and give them suggestions for action, instead of an abstract number.

We expected the avoidance of numerical figures in diabetes care to be considered a more radical move than in hearing care, since the control of blood sugar values is an essential part of diabetes treatment. However, several of our Novo Nordisk visitors welcomed the idea: ‘I very much like the thought of moving away from numbers, and also in some way turn away from a reactive to a proactive approach.’ The tool was here interpreted as a ‘proactive’ approach, contrasted with a currently ‘reactive’ approach of insulin treatment.

During one of our guided tours, two employees from Novo Nordisk talked about the concept. Naja, from the department Concept and Innovation Facilitation pointed out that the concept assumed that people want to change their blood sugar levels. Christel, who works with patient education, disagreed:

Naja: There is one basic assumption that lies under this - which is people want to do something about their blood sugar - if you do not agree with the basics, it will not help you.

Christel: I am not sure, because some people measure their blood sugar and will not know what to do about it. They just get the number, and do not do anything.

Naja: Yeah…

Christel: They just look at it, and do not know how to react to it. This could be good – to say: Today, you might not eat as much sugar.

Naja: So doctors take for granted that you know what to do about a blood sugar at nine in the morning..?

Christel: I have heard from patients at [the name of a diabetes outpatient clinic] who are told to measure, that they are not told anything about what to do with the test result.

While Naja suggests that some patients may not wish to bring down their blood sugar levels, Christel argues that wanting to bring down numbers does not have to be a premise; on the contrary, many people have difficulty relating to the numbers. She suggested that it might be easier to act on the basis of tangible advice, than from a number that requires interpretation. The conversation is about how people relate to and struggle with meaningless numbers, but it also articulates different understandings of diabetes treatment. Dismissing the premise that treatment is a matter of lowering blood sugar values, Christel proposed an alternate reading, in which diabetes treatment is about setting small but tangible goals. It does not require people to want to lower their numbers, and focuses less on choice and more on action. The avoidance of numbers brought forward aspects of the problems of diabetes that had not been articulated in the earlier discussion about the need for patients to accept the condition and acquire an appropriate understanding of future risk of complications. Taking part in this discussion, another visitor wrote: 'The app idea is excellent, tied into the idea of getting away from numbers – changing habits is so challenging for most people.' In this comment, treatment is not about making a treatment choice, but about changing everyday habits. It foregrounds another aspect of human action and the problem of diabetes than the earlier discussions. However, as an innovation advisor, Mikkel, from Novo Nordisk, said: 'This is hard. It is interesting as such [to avoid numbers], but it is very difficult for me to react to this personally, because I just want a number. I mean, I belong to the category of people who wants a number and a graph.' We talked about the role numbers play in diabetes treatment, and I suggested that the emphasis on numbers sometimes make people focus too much on the blood sugar and less on other aspects of diabetes treatment. Mikkel objected: 'an app that simply provides recommendations can potentially be fatal if the patient needs a specific medical treatment to lower their blood sugar level.' He articulated a dilemma in the reframing of the role of measurements: while avoiding numbers could be a way to change everyday habits and be proactive in diabetes treatment as other employees observed, it also posed a risk of masking the 'true' stage of the condition and the vital need for medication to control the blood sugar.

People from both companies reconsidered the role of measurements and paid more attention to experiences in the case of hearing and to actions in the case of diabetes. However, in the ensuing discussions, employees tested the boundaries of this alternate approach both from their own preferences and from a stance about how their organization could best intervene in health care issues. Reframing hearing loss as a family experience was challenged by the understanding of the boundaries of Oticon's business which was treat hearing problems, implying a differentiation between hearing issues and other communication problems. The separation of measured from experienced loss also resulted in an observation about how the two are related. The reframing of diabetes treatment into a matter of actions, was by some articulated as a valuable opportunity to adopt a positive and proactive approach. In these comments, human action was not articulated as a matter of calculated choice, but emerging from everyday habits. This reframing however, also breached with and articulated the understanding that diabetes treatment is about controlling the glucose level.

Designing visible treatment?

During my fieldwork, it became clear to me, that both Novo Nordisk and Oticon work according to the understanding that treatment devices preferably should be as discreet as possible. In the entrance hall at Oticon's headquarters a poster depicts the evolution of hearing aids from the cumbersome hearing trumpet to the tiny digital hearing aid. While I was affiliated with Oticon, a new hearing aid - Intiga invisible - was launched. The aid was small and discreet, designed specifically for new users of hearing aids who their devices to be unnoticeable (Oticon 2012). The sales literature described it as 'designed to keep your hearing loss out of sight, out of mind' (Oticon 2012). A similar assumption seemed to underpin Novo Nordisk's insulin pen. The company was the first on the insulin market to introduce a pen to administer the injections. Previously injections were done with syringes, and apart from being difficult to handle and painful to use, syringes looked like medical equipment. In contrast, the insulin pen is 'similar in appearance to a fountain pen' (Novo Nordisk 2014c). In both companies the ideal of designing for discretion, builds on an understanding that the conditions and their treatments should be kept out of sight. While the intention is to meet the wish of their users, the producers may also reinforce the premise by working from it. In the exhibition, two design concepts turn this premise on its head, and make the treatment technologies visible, to engage employees in a discussion of the consequences of a rendering treatment visible.

The Revealable Hearing Aid lights up when the wearer needs extra help to hear. While the design for invisibility of hearing aids both reinforces the idea that hearing loss is embarrassing, and suggests that the problem can be solved discreetly on the body of the impaired person, the Revealable Hearing Aid gives a visible presence to communication problems and treats them as social problems. The Revealable Hearing Aid can be set in an automatic mode and responds to the amount of noise in a setting by lighting up. The wearer can turn the lights on and off at will. The aid encourages other people to engage more actively in making the communication flow when the aid lights up. It embraces the observation that even when with a hearing aid, some situations remain difficult. Rather than concealing these problems and setting a 'trap' for consideration of

The Revealable Hearing Aid lights up in situations where the wearer needs extra help.

other solutions (Ingold 2012), it renders hearing problems visible and solvable. It thereby makes the work of repairing communication a shared responsibility.

The comments about the visible hearing aid that people left at the stand conveyed a disruption of ordinary assumptions, and articulated what an employee from Oticon called an 'industry fetish': 'Quite provocative... The 'invisible hearing aid' is an industry fetish.' The familiarity of this social norm or 'fetish,' was discernible in some of the strong reactions to our interruption of it: 'Sorry everybody has some degree of vanity. Would you seriously use this yourself?' In this reaction, the critical design concept was depicted as lacking empathy with the users and their concern for appearances. Another participant pointed out that the visible aid might even be harmful its users: 'Don't like this concept. May stigmatize the hearing-impaired person.' The concept was deliberately provocative, calculated to subvert common assumptions. Crabtree describes 'provocative design' as: 'artefacts that produce interruptions or tears and rents in ordinary activities and which provide fleeting glimpses of the organizational fabric of social life' (Crabtree 2004). He compares the critical interventions to 'breaching experiments' in ethnomethodology: experiments designed to produce confusion by violating social norms and render visible the background expectations of everyday social life (Garfinkel 1967:37, 58). In other words, breaching experiments are demonstrations through which the 'strangeness of an obstinately familiar world can be detected' (ibid:38). By breaching concerns about vanity and stigma, the Revealable Hearing Aid rendered visible the importance of these issues in how employees picture their users.

While the visible aid provoked strong some reactions, others appreciated the idea. According to one employee, 'This is a concept we have discussed earlier on. I buy into the argument, and agree that some people would like a sign that says "I am hard of hearing," making it easier for other people to adjust their communication. In practice you should be able to turn it off.' What was a very provocative concept for some people was recognized by this person as something that had already been discussed. A few days after the exhibition, I was having lunch with Torsten, a visiting engineer working in the research department at Oticon. He suggested that the Revealable Hearing Aid could be used as a prototype for exploring the impact of an interactive hearing aid in conversations. He pointed out that hearing-impaired people often keep the flow of conversations, even when they are missing out on the content, and showed me an article on the topic. He suggested thinking of the Revealable Hearing Aid as a way of making the communication partner aware of the hearing difficulty, without the impaired having to say 'excuse me' and thus taking off some of the work load of repairing conversations. I got a glimpse of how an idea might 'develop with people' (Mack et al. 2013); Torsten related the Revealable Hearing Aid to the literature on talk-in-interaction, to an existing prototype that could be rebuilt into a working prototype, he associated it with the understanding that hearing-impaired people are burdened with repairing communication, and suggested designing a new research project with it. The original concept was reworked, and maybe caused a 'modest intervention within ongoing, continually shifting and unfolding, landscapes of transformation' (Suchman 2011:16).

The corresponding device for insulin treatment was a redesign of the insulin pen. It taps into the perception that insulin treatment is a complex regime that limits activities of everyday life, as patients will have to carry the insulin with them and inject several times a day. The Once Daily Device is designed to be left on a table to signal that it belongs in the home, not in a purse or a pocket. While the design of the insulin pen communicates simplicity of use, the Once Daily Device communicates simplicity of routine: insulin therapy may start with a basal dose that is injected only once or twice a day. This concept was not as controversial the Revealable Hearing Aid, perhaps because it was not considered to interfere with the empathy for its users. As one visitor wrote: 'Sympathetic idea, but may feel like yet another device/prop in my stuffed life. Maybe a 'cradle' for my pen instead?' The comment indicates that the concept was sympathetic to its users' concerns, but it also shows that the design idea was not only treated as embodied

The Once Daily Device communicates simplicity of the daily routine that involves injections of just one daily basal insulin dose.

ethnography allowing people to comment on the idea behind the design, but as a possibly implementable design concept. It is related to as a thing that can be modified or changed. As I observed earlier, the ‘thinginess’ of medicines promises the capacity of transformation because of its concreteness. Likewise the thinginess of design allowed people to work with and transform the concept. Other comments on this concept however, also made it visible that ideas and how they can be reworked is located in an organizational context and situated in relation to business strategies: ‘Good idea, and an idea we will revisit again. But it is challenged by our ‘one device for all regimens’ strategy.’ The business strategy of a coherent device design across all types of insulin, whether the patient only needs a basal dose or needs more frequent injections, made it difficult to argue for a special design for new users.

Rendering treatment devices visible resulted in a variety of interpretations and images of possible consequences of the visibility. The Revealable Hearing Aid produced a breach with an ‘industry fetish’ and concern for making hearing aids invisible. It also disrupted and thereby articulated the assumption that potential users fear stigmatization and are concerned about appearances. To other people in the organization, however, designing a visible hearing aid was not provocative and or even new; it was seen as a potentially useful way of signaling a need for support in communication. Playing with the possibility for designing a visible hearing aid brought about other aspects of impairment. It articulated the understanding that hearing aids do not restore hearing to normal, and the impaired person may be burdened with the responsibility for repairing communication, while the visible design would encourage communication partners to help. Rendering the insulin injection visible was not taken to breach norms about stigma, but more importantly the norm of a uniform design strategy in the organization.

The visible treatment concepts were intended to open up the problem-solution framework of hearing aids and insulin injection devices (cf. Anderson). 'Opening up' however only happens in relation to people and their current understandings, and as Suchman observes we need to recognize the limits of creating something 'new' within an organization (2011). She points out that the generation of new ideas is always situational; it is received by people and reworked. In their work on 'social shaping of innovation,' Mack and colleagues emphasize the need to pay attention to organizational realities and recognize that 'ideas develop with people' over time and through interaction among employees (2013). According to Suchman, it is an ongoing process in a landscape of transformation made up by a myriad of minor changes (2011:16).

In these pages, I have shown that our material in some instances engaged people in discussing issues that were 'new' to them and articulated the possible reframing of current approaches to the conditions. Other people considered the ideas behind the exhibition to be old news, which in some cases elicited other observations about their view on the problem of hearing loss, as when Per explained to me that Oticon was already moving away from measurements. In other situations, the exhibition revived old ideas, as when Torsten played with the idea of developing a prototype of the Revealable Hearing Aid. The newness of our material depended on the people who read it and we may consider their engagements with the ethnographic material and designs as matters of situated reframings. People related to the ideas by connecting them to previous experiences with similar or different tools, to company design strategies, personal convictions and assumptions about the users. From this observation, it seems less relevant if our stance was *new* or not, and more interesting that it did – at least for a while – stimulate conversations that brought into play different assumptions about users and how best to design for their problems. In that sense it opened up the problems-solution framework, and underlying assumptions were articulated and reframed.

CONCLUSION

In this chapter I have turned my attention to the companies and their employees. I have displaced my attention from doctors, patients, measuring tools and treatment devices in order to scrutinize the assumptions and logics about users that are at play in the companies.

With the exhibition we intended to open up for discussions about the assumptions underlying the problem-solution framework of hearing aids and insulin pens. We suggested that medical conditions are matters-in-the-making that appear in a myriad of versions by juxtaposing ethnographic material from diverse settings and instances of interaction. This shared ethnographic material was presented along with suggestive analytical questions to encourage engagement and instigate discussions rather than providing ‘insights’ about users. The introductory question about problems and solutions framed our exhibition as a deliberate attempt to interrupt the understanding that treatment technologies merely treat and thereby solve medical problems. The critical concepts were designed to breach commonly accepted assumptions about the relation between the problems of chronic medical conditions and their treatments. The juxtaposition of the two medical conditions reflected the comparative, analytical strategy of depriving assumptions about each disease area of their familiarity.

The ethnographic material and critical design concepts provoked discussions about the problems of diabetes and hearing loss, and reframings of the role of measuring and treatment technologies. Many comments articulated and reflected a rational model of action; that patients need to understand their condition and accept that it is a serious matter with possible future implications for their health. Based on this understanding of their medical condition, patients were assumed to take action and start medical treatment to prevent future risks. In this model, there is a truth about causalities, and the assumption is that human decision making results from a ‘process of computation’ (Cohn 2000). However, the assumptions underlying the rational model were also made the subject of critical conversations as employees discussed how far doctors should go to motivate their patients, and it was suggested that Oticon should not take part in creating any treatment needs that were not felt and realized by the hearing-impaired person. It drew a distinction between the true existence of a measurable hearing loss, and what was true to the patient. As our visitors rethought the role of measurement in hearing care, the polar opposite of a measurable loss was articulated; hearing was addressed as primarily a shared experience of the family. This alternate approach to hearing loss began a discussion of Oticon’s role in treatment, and some questioned if it was even possible to intervene in the home setting, while others argued that Oticon should continue developing a counselling tool. In rethinking the role of measurements in diabetes the difficulty of interpreting numbers and making them actionable was articulated. An alternate approach to human action was brought into play as diabetes treatment was addressed as a matter of taking action day by day and changing everyday habits. However, eliminating numbers was problematic, since diabetes treatment is also about controlling blood glucose to prevent fatal consequences.

The variety and sometimes the disagreements in the comments we received made it clear that we cannot think of the companies as units; what might be provocative and novel to one employee is easily recognizable to another. People meaningfully related to the exhibits by making connections to previous work experiences, corporate strategies, logics about their users, understandings of what makes a 'good' solution and to personal preferences. We may read their comments and listen to their conversations as situated reframings. Much like the way I argue that we treat patients' accounts about their diseases, we may treat employees' comments as a matter of connecting, contextualizing and analyzing. While I observed that diseases are articulated in a myriad of ways, it seems inevitable that assumptions and logics about users are subject to a similar variety of articulations and interpretive transformations. The diversity of reactions revealed that the 'barriers to treatment' stance, that I took as the starting point and vehicle for my analysis over the past chapters, does not fully reflect the complex and diverse understandings of users within the companies. The 'barriers to treatment' stance might better be seen as a 'pure' form that has worked as a tool for analysis; a 'distilled' and coherent concept filtered from messy practices (Mol 2008:10).

CHAPTER SEVEN

CONCLUSION

For persons living with hearing impairment or diabetes, the relevance of treatment with hearing aids or insulin injections emerges from interplay between measurements of the body, meaningful readings the test results, interpretive transformations of past events and experiences, and in relation to ways of accommodating the medical condition. In other words, making these medical conditions treatable is a practical, interactional accomplishment. I have denoted this practice 'treatability.'

I opened my dissertation by bracketing the common understanding that medical conditions are 'treatable,' when they respond to treatment with a given device or medicine. From this starting point, I engaged in an empirical investigation of the ways in which doctors, patients and family members deal with hearing loss and diabetes and relate to the relevance of treatment. Through four analytical chapters, I have unfolded my argument by examining how measurements are produced and rendered meaningful in clinical encounters (chapter three), how people assess and deal with their medical conditions as they go about their everyday lives (chapter four), how hearing aids and insulin injections affect the problems they are designed to solve (chapter five) and finally what assumptions and logics about the potential users of hearing aids and insulin injections, that are at play in the two device manufacturing companies with which I collaborated (chapter six).

In closing my dissertation, I will look back at what we learned in each chapter. Thereafter I will consider the consequences of my analytical strategy and suggest some implications of moving beyond ‘barriers to treatment.’

Displacements and contrasts

The embodied practices of handling chronic conditions and rendering them relevant to treatment comprise the empirical ground of my study. I have structured my account around ethnographic contrasts, by virtue of which everyday practices are rendered more visible. The ethnographic contrasting entailed two different movements. The first was an ongoing comparison of hearing loss and diabetes. The other was a displacement between settings and situations of people interacting and relating to the medical conditions and their treatments. Over the course of my thesis, I moved among the clinical encounter, the homes of my informants and the two medical device manufactures I have worked with. In addition to the two ethnographic contrasts, the strategy of comparing my empirical inquiry of how the relevance of treatment is practically achieved to the stance I have termed ‘barriers to treatment,’ constitutes an analytical contrast.

I prepared the ground for my analytical contrast in chapter one, where I unfolded the ‘barriers to treatment’ stance. It was developed from the observation, that the prevalence of type 2 diabetes and acquired hearing loss have increased over the past decades and are predicted to continue doing so. In spite of extensive documentation of the effect of treating these chronic medical conditions, a considerable number of people do not receive any treatment. That raises the question: what are the barriers to treatment? An underlying assumption is that people who suffer from diabetes or hearing loss need to realize both the severity of their condition – the risk of complications of diabetes and the association of hearing loss with social isolation, depression and poor health – and the advantages of early treatment. The role of health care professionals is to educate, inform and support their patients in making the right choices. The onset of treatment is a linear movement from a medical diagnosis through patient acceptance and motivation to initiate use. In contrast to this stance, I developed a different account about treatable medical conditions: a story that attends to the practical accomplishment of rendering treatment relevant - or not - in particular situations. It draws on the turn towards practice in the fields of anthropology and sociology. It is a telling that starts from a primacy of interactions and examines the relations among persons, bodies, ailments and treatments as they unfold on particular occasions. It involves a shift from the focus on barriers, to practices of interrogating and handling a chronic medical condition.

In the second chapter, I discussed the ways in which I studied these situated practices. I explained the premises I worked within, the setting in which my research took place and the methods I used. I argued that, like any object of knowledge, the research in my field was accomplished through interactional *work*. To render visible the premises of this work, I discussed my relation with the two medical companies, my collaboration with design and my work with the ethnomethodological frame of the project. I then situated doctors and patients in the treatment landscapes. Subsequently, I discussed how I gathered my ethnographic material by observing clinical encounters, talking to people in their homes and asking them to observe their everyday practices for dealing with the chronic medical condition. The chapter demonstrated the partiality of my ethnography and analytical work by accounting for the path I followed.

The third chapter marked the start of my empirical investigation. It built on ethnographic material from the clinics, where I observed doctors and patients in their clinical encounters. I left behind the assumption that treatable medical conditions exist prior to practices of knowing, and engaged an empirical examination of how hearing loss and diabetes are locally produced and rendered meaningful. I observed that the object of clinical medicine is carefully produced through collaborative work. This embodied practice takes active participation from the patient who transforms his or her body into an object of clinical investigation and from the doctor who examines and consciously selects certain 'data' that are of relevance to his or her medical practice. Measuring tools mediate these practices; the audiometer draws attention to hearable pure tones in the production of hearing loss and blood glucose meters draw attention to the level of sugar in the blood. While medical evidence is often treated as a truthful answer to prior uncertainties, I noted that audiograms and blood sugar tests often gave rise to new questions and further inquiries. The numerical figures were rendered meaningful as they were related to the patient's account about past events and experiences. In the process, past activities and everyday habits were transformed into matters of 'lifestyle' in diabetes care, and to matters of 'life conditions' in hearing care. Both the measurable object of clinical practice and the experiencing subject emerge from interactions and mutually inform each other.

In the fourth chapter, I moved beyond the clinical encounter and into the homes of my informants. In contrast to the clinics, where rendering medical conditions observable was the focal point of everyday activities, the ailments were often imperceptible to the people as they went about their everyday lives. The dubious character of both hearing loss and diabetes contributed to the problems people were facing. Hearing loss may disrupt the flow of interactions in situations where it is hard to hear. But when the person is alone or in a quiet space, the hearing impairment may seem to have vanished until other people make him or her aware that he or she had not heard something. That gives rise to an uncertainty as to whether the person did not hear, or there was nothing to be heard. In the clinic, hearing impairment emerged as a sensory capacity that may be measured with audiometry and experienced by the patient. In the home, by contrast, hearing loss was located in its consequences on social interaction. It is relational and dependent on circumstances, spaces, sounds and how people actively accommodate or pre-empt disruptions. For most of my informants with diabetes, symptoms were few and measurements played an important part in how they handled their medical conditions. However, measurements did not only assess their diabetes, but the numbers also made it possible to set tangible goals and transform a distant future risk to a short term achievements in accordance with the quarterly measurements of the long term blood sugar. It allowed people to act upon their diabetes. Nonetheless, diabetes remained capricious and unexpected changes might occur. From situated concerns, my informants engaged in assessing, transforming, counteracting and pre-empting their medical conditions. I first treated their stories as descriptions of these everyday practices, inspired by Mol's praxiographic approach (2002). However, I also realized that practices and meaning cannot be separated. While an act has appearance and can be observed, it is 'what appears to be' that is critical (Gubrium and Holstein 1993). In other words, I needed to treat people's stories not as mere descriptions of events but as situated analysis, a practice of connecting and interpreting past events.

In the fifth chapter, I contended that the problems of diabetes and hearing loss are mediated by the technologies designed to treat them. In contrast to the assumption underlying 'barriers to treatment' – that medical conditions are first diagnosed, then accepted by the patient and finally treated – I argued that there is no such linear sequence of problem-choice-solution. With the concept of 'configuration,' I analyzed the treatment technologies as materialized figuration or arrangements that affect particular meaningful associations of persons and objects (Suchman 2007). For hearing loss, I observed that a hearing aid that amplifies surrounding sounds into the ear canal figures hearing loss as a physical and sensory impairment. For diabetes, I found that insulin, which lowers the level of glucose in the blood, figures the diabetes as a matter of elevated blood sugar. That is not to say that medical conditions are determined by their treatments. Objects, such as bodies, diseases and treatment technologies have an indeterminate quality as they are subject to interpretive transformations (Gubrium and Holstein 1993, Gubrium and Lynott 1987). Medical conditions emerge in relations to technologies and humans.

In the sixth chapter, I changed settings and turned to the two medical companies. My analytical attention was on the assumptions and logics about potential users that are at play in the companies. In the previous chapters, the 'barriers to treatment' stance had enabled me to structure my analysis, by forming a contrast to my inquiry of treatability. It was however an abstract and distilled concept that does not fully reflect the complex ways in which the people in the companies depicted the potential users of the devices. The empirical ground of my analysis was an exhibition we arranged as a closing event of our research project. In the chapter, I listened to the conversations amongst employees and revealed how assumptions about their products, the medical conditions and potential users were articulated. During the conversations, our visitors reframed the role of measurements, motivation and the relation between medical problems and technological solutions. Like everyone else who inhabits this dissertation, they constructively engage their worlds and actively render it meaningful.

Consequences of 'treatability'

The commitment to situated practices and primacy of interactions that constitutes the ground of my work, entails corresponding shifts in the approach to the study of treatable medical conditions.

The first shift concerns the empirical attention. The rational model that I have termed 'barriers to treatment,' works from the premise that hearing loss and diabetes are treatable; the treatable character of the medical conditions is taken for granted and forms the premise for the study of barriers. In my work, I turn the matter of treatability into an empirical question. This shift involves an attention to the procedures, methods and techniques for constructing and maintaining what we commonly take for granted (Mol 2002, Gubrium and Holstein 1997). Rather than assuming a given relation between an ailment of the body and a treatment, I sought actual occasions when persons, bodies, disease and treatments were related.

The second shift is in the conceptualization of the relation between human beings and their world. The turn towards practice involves a movement away from perspectives; away from the understanding that diseases are perceived from a variety of subjective perspectives of nurses, doctors, patients and family members (Mol 2002), as if people were mere spectators gazing at the same object and experience took place only in the mind (Dewey 1929). Turning towards practice entails that we see people as active participators in a social and material world, who learn about the world as they engage in handling problematic situations. For people who are living with a chronic medical condition, the relevance of treatment is a matter of practical inquiry, an embodied and concrete practice.

Finally, the primacy of interaction entails a shift in the analytical approach to human action. In the rational model, choices and barriers are ascribed great importance for human action. Attending to practices of treatability, by contrast, people's engagements with dubious and unpredictable health conditions are matters of locating problems and experimenting with solutions. While I do recognize that hearings aids are often associated with old age and disability, and insulin injections are associated with invasion of the body and the guilt of having lived an unhealthy life, I suggest that we do not see these as 'barriers' to human action. If we do so, we would assume that a barrier or motive preceded and determines action; that a sequence of events follows after a pristine moment of choice. Instead we may see them as shared cultural understandings of hearing aids and insulin that are put to use, when people make their actions accountable in a post hoc analysis. In other words, they do not determine action but form part of the problems and dilemmas people are dealing with. In my retelling of treatable medical conditions, my attention is therefore on the methods through which people construct and sustain treatable conditions.

Beyond barriers

I would like to conclude this dissertation by thinking about some of the perspectives that are opened up when we leave choices, barriers and motives behind and attend to practices of treatability.

Attending to these practices changes the approach of medical device manufactures to the problem of chronic medical conditions. Attending to practices of treatability opens up the problem-solution framework of the design of hearing aids and insulin injections. Given that hearing loss and diabetes are rendered meaningful in relations with treatment technologies, manufactures may anticipate the mediating role of technologies (see also Verbeek 2008). In our closing exhibition, we thus suggested that diseases are figured with treatment technologies, and consequently may be figured differently (Suchman 2007:227). We presented alternate tools for measuring hearing loss and diabetes as ways of relating differently to the two medical conditions. For hearing loss, a tool for shared assessment drew attention to the social consequences of hearing loss more than the measurable loss of audibility. For diabetes, a design concept suggested assessing the active attempts of changing habits, rather than focusing on levels of glucose in the blood. We also suggested anticipating the role of treatment technologies by reconsidering the assumption that devices should be ‘out of sight and out of mind’ (Oticon 2012) to accommodate an assumed fear of stigmatization amongst people new to treatment. Instead of solving hearing problems discreetly on the body of the hearing impaired, we suggested that a revealable hearing aid reminds communication partners about the wearer’s need for assistance with communication. Rather than designing insulin injection devices to be discreet and portable, a device to be left standing at home communicates simplicity of a routine that often involves only one daily injection. These design concepts not only suggest how manufactures may address medical conditions differently but serve as a reminder that treatment technologies do not only solve problems, but also take part in constituting them.

The relational aspect of treatability has consequences beyond the manufactures of treatment devices, as it changes how we problematize chronic medical conditions more broadly. The relevance of treatment is not primarily a matter of an individual realizing and accepting his or her diagnosis and choosing to start appropriate treatment. As an alternative to the abiding concern for individual choice, Mol has suggested that we think of doctors and patients as engaged in 'shared doctoring,' as they experiment with different solutions to a chronic health problem. In this approach doctors do not primarily educate and motivate their patients to make the right choices; doctors and patient inventively and persistently 'tinker' with different solutions (Mol 2008:54 ff). Choices are indeed made, but do not determine a sequence of events. They form part of an ongoing care process.

I have developed my analytical attention to treatability in relation to two chronic medical conditions, but it may also be applicable to other disease areas. It encourages consideration of the role technological devices or medicines play in rendering diseases relevant to treatment. It steers attention towards practices of relating. Applying this approach to other disease areas would involve an abiding concern for how humans in relation to technologies render diseases relevant (or irrelevant) to treatment.

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ENGLISH SUMMARY

This thesis is an ethnographic study of how doctors and patients in Denmark and United States of America deal with hearing impairment and diabetes in their patients. Both conditions are considered treatable with modern technologies; the former with a hearing aid and the latter with insulin injections amongst other treatments. In my work, I bracket this common understanding of 'treatable,' in favor of an empirical investigation. I argue that we need to seek out the actual occasions on which persons, bodies, afflictions, measurements and treatments are related to each other so that treatment is made relevant or not; I term this practical accomplishment 'treatability.'

My interest in these issues emerged from my involvement in the research project 'Innovating with pre-users of medical devices.' The project was initiated in collaboration between Novo Nordisk, which manufactures insulin injection devices, Oticon, which produces hearing aids and the SPIRE Research Centre at the University of Southern Denmark. The two companies shared an interest in the paradox that people with a chronic medical condition delay beginning the use of treatment technologies until well past the point at which they could benefit from them. Both hearing loss and diabetes are chronic and incurable conditions that but can be managed with technological treatment devices. Left untreated, both can have severe consequences. My task on the project was to identify the barriers that keep people from becoming users of medical technologies. The project was conducted in close collaboration with a product designer responsible for developing methods of involving 'pre-users' in innovation processes.

During ten months of fieldwork, I visited several medical clinics, where I observed doctors and patients as they examined medical conditions, discussed test results and worked out treatment plans. I also visited patients in their homes, to understand how living with hearing loss or diabetes is done in the context of everyday life. However this thesis does not reveal the paradox of delayed onset of treatment. It does something else. It turns the common assumption, that medical conditions are treatable if they respond to an available treatment, on its head. Rather than assuming we know what the problems of diabetes and hearing loss are, the thesis explores how these medical conditions appear problematic and are practically dealt with in clinical encounters and in the everyday lives of people who live with them. It shifts away from a question about

‘barriers to treatment’ and to an examination of the interactional productions of treatable conditions. The study is informed by the turn towards practice in the fields of anthropology and sociology, and starts from a primacy of interaction. The existence and maintenance of the world we take for granted is the result of laborious interactions and interpretive work, and I examine how the apparent concreteness of the world we inhabit is assembled. I depict human action not as a matter of accordance or lack thereof with a given rational use of medical treatments, but as embodied, situated practice.

The empirical investigation is structured as a movement between different occasions, on which people handle the problems of hearing loss or diabetes. I examine how doctors, patients and their families inquire and accommodate the medical conditions by locating and solving what to them are problematic situations. The displacement between different sites renders visible the mundane practices and situational differences of each site by virtue of contrasts.

In the clinics, doctors and patients often relate to the medical conditions by way of measurements, numbers or graphs. They are not merely detected by the doctors; the object of clinical medicine is carefully produced through collaborative work. It takes active participation of the patient, who transforms his or her body into an object of clinical investigation. It also takes skillful work of the doctor, who produces data about the disease and constitutes an object of relevance to medical practice. While medical evidence is often treated as a truthful answer to prior uncertainties, I observe that audiograms and blood sugar tests often give rise to new questions and uncertainties. The numerical figures are rendered meaningful as they are related to the patient’s account about past events or experiences. The medical evidence and patient experiences mutually inform each other; the patient’s account makes certain explanations of the medical evidence available, while test results steer the direction of further inquiries into the patient’s experience and everyday habits. In the process, past events and everyday habits are transformed into matters of lifestyle in diabetes care, and to matters of life conditions in hearing care. From the clinical encounters we learn that patients are granted quite different epistemic authorities. A patient with hearing impairment is ascribed authority to assess his or her hearing experience and this assessment is a central element in his or her construction of the hearing impairment. A patient with diabetes, on the other hand, is given little authority to assess his or her health condition, as the sense of well-being is not ascribed the same importance. This is but one of the differences that is articulated by virtue of the contrast between the disease areas.

In the home, hearing loss and diabetes are obviously handled quite differently. In contrast to the clinic, where doctors and patients are dedicated to inquiring into and treating the ailments, both hearing loss and diabetes emerge more dubiously in the home. Hearing impairment may be obvious in noisy situations, where it is hard to keep a conversation going, but in many other situations it may not cause difficulties at all. Diabetes, in its early stages and when well regulated, may hardly be noticeable for the patient. My inquiry into the everyday practices for dealing with hearing loss or diabetes at home starts from the apparent invisibility and capriciousness for the people who were living with them. I show that hearing loss is relational; it emerges in relation to specific circumstances, spaces, sounds and other people's abilities to hear. It is handled by moving closer, paying attention and avoiding noisy places and crowds. It is changed by, but also changes the situation. Handling diabetes is closely related to measurements that tell if the condition is in control. However, measuring technologies do more than just measure. They allow people to gain control, translate a distant future risk to tangible short term treatment goals and create simplicity in a complex and overwhelming information on diabetes. Diabetes, however, remains capricious as complications may occur unexpectedly. The people with diabetes that I met, experimented with ways of acting upon their condition and transforming the imperative of healthy living, so it did not colonize their everyday lives. From situated concerns, my informants engaged in assessing, transforming, counteracting and pre-empting their medical conditions.

Diabetes and hearing loss are mediated by the technologies that have been designed to treat them. They are not merely revealed by doctors, diagnosed and then treated. Such linearity of events assumes that diseases occur independently of their treatments and masks the enmeshment of the medical problem and available solutions. With the concept configuration, I analyze the treatment technologies as materialized figuration, or arrangements that affect particular meaningful associations of persons and objects. In relation to a hearing aid, hearing loss is figured as a sensory impairment that can be treated by amplification of surrounding sounds into the ear canal. This solution draws attention to the physical impairment of the individual body, as opposed to the relational character of hearing loss that emerges with the mundane practices of accommodating disruptions of conversations. In relation to the insulin injections, diabetes is figured as a matter of increased blood sugar levels that needs lowered with medication. This solution draws attention to the numerical figures in diabetes care and one way of keeping them in control, as opposed to other ways of keeping the level of blood glucose with normal ranges and other aspects of diabetes care. That is not to say that medical technologies determine particular figurations of the medical conditions; the prefix of *con-* reminds us that the technology is figured *with* humans, and I argue that medical conditions emerge in relations between persons, measuring devices and treatment technologies.

In the companies, we presented extracts our ethnographic material, analytical thoughts and design concepts in an exhibition that asked its audience, 'Do we create problems and solutions?' The aim was to articulate the assumptions that underlie the design of hearing aids and insulin pens and provoke discussions about the relation between the problems of the chronic medical conditions and the treatment devices. One assumption that was clearly articulated in the conversations among the employees during our exhibition was that patients need to realize the health risk they are facing, so they will take action in time. The concept of motivation emerged as a key element in this image of patients new to treatment. The fear of stigmatization was amongst the explanations employees brought up for why some people are reluctant to start treatment. Health care professionals were sought to educate, understand and support their patients so they would understand their need for treatment and become ready to start. These assumptions resonate with the model that I call 'barriers to treatment.' However, the assumptions were also made subject of discussions and revisions. The predominant role often ascribed to measurements and medical evidence was discussed, as were the assumptions underlying the design of hearing aids and insulin pens. For example, it was suggested that hearing loss should be addressed as a shared experience of the whole family, more than a measurable loss of audibility. Other participants observed that numerical figures can be difficult for patients to act upon, and other ways of engaging them were considered. Their situated reframings made it clear that 'barriers to treatment' did not fully reflect the divergence of understandings of users that were at play in the companies.

Attending to treatability as a practical accomplishment opens up an analysis across material and social relations; how interacting persons meaningfully relate to measurements, medical conditions and treatment devices. It entails that there is no linear path, with barriers in its way, from the detection of a medical condition to the onset of treatment. Treatable medical conditions emerge from situated practices and the inquiry of health problems is enmeshed with possible solutions.

DANISH SUMMARY

Denne afhandling udgør et etnografisk studie af, hvordan læger og patienter i Danmark og USA håndterer hørenedsættelse og diabetes. Begge tilstande betragtes sædvanligvis som behandlelige fordi de kan afhjælpes med moderne behandlings teknologier; førstnævnte med høreapparater og sidstnævnte med injektion af insulin, blandt andet. I mit arbejde, tilsidesætter jeg imidlertid denne almene forståelse af forholdet mellem en sygdom og dens behandling til fordel for en empirisk undersøgelse. Jeg foreslår, at vi i stedet iagttager de konkrete situationer, hvori mennesker, kroppe, helbredstilstande, målinger og behandlinger relateres til hinanden således at behandlingen fremstår enten relevant eller irrelevant. Relevans af behandling er med andre ord en praktisk bedrift.

Min interesse i disse spørgsmål er udsprunget af min deltagelse i forskningsprojektet 'Innovating with pre-users of medical devices'. Projektet blev opdraget i et samarbejde mellem Novo Nordisk, der blandt andet producerer insulinpenne, Oticon der producerer høreapparater og forskningscenteret SPIRE ved Syddansk Universitet. Begge virksomheder var interesserede i at forstå det tilsyneladende paradoks, at mennesker med en kronisk helbredstilstand ofte udskyder opstarten af behandling til trods for den dokumenterede helbredsgevinst ved at starte rettidigt. Både hørenedsættelse og diabetes er kroniske og uhelbredelige, men kan behandles med medicinske teknologier. Begge tilstande kan udvikle sig og kan få alvorlige konsekvenser, hvis de ikke behandles. Min opgave på projektet var, at identificere de barrierer, der afholder folk fra at blive brugere af de medicinske teknologier. Jeg gennemførte projektet i tæt samarbejde med en produktdesigner, som havde til opgave at udvikle nye innovationsmetoder til at involvere disse før-brugere i designprocesser.

I løbet af mit 10 måneder lange feltarbejde besøgte jeg en række klinikker, hvor jeg iagttog læger og patienter mens de undersøgte helbredstilstande, diskuterede medicinske prøveresultater og udarbejdede behandlingsplaner. Jeg besøgte også patienter i deres hjem, for at forstå hvordan de levede med hørenedsættelse eller diabetes som del af hverdagen. Det til trods, kaster min afhandling ikke lys over det tilsyneladende paradoks, som virksomhederne havde identificeret. Jeg omgør derimod den udbredte antagelse, at helbredstilstande er behandlelige, hvis de

responderer på en given behandling. Frem for at formode, at vi allerede ved, hvad der udgør problemet med hørenedsættelse og diabetes, udforsker denne afhandling hvordan problemer med disse kroniske helbredstilstande praktisk håndteres i medicinske konsultationer og som del af hverdagslivet. Det forskyder spørgsmålet om 'barriererne til behandling' til en undersøgelse af, hvordan behandlelige helbredstilstande praktisk konstrueres. Mit arbejde tager afsæt i antropologiske og sociologiske praksisstudier, der beskæftiger sig med sociale og materielle interaktioner. Dermed betragtes eksistensen og opretholdelsen af den verden vi normalt tager for givet, som resultat af arbejdsomme interaktioner og fortolkninger, og jeg undersøger hvordan konkretheden af den verden, vi bebor, er produceret. Jeg betragter ikke menneskelig handling som et spørgsmål om efterlevelse af en rationel brug af medicinske behandlinger eller mangel på samme, men som kropslig, materiel og situeret praksis.

Den empiriske undersøgelse er struktureret som en bevægelse mellem forskellige situationer, hvori mennesker håndterer de problemer hørenedsættelse eller diabetes frembringer. Jeg undersøger hvordan læger, patienter og deres familier forstår og håndterer helbredstilstande ved at lokalisere og løse, hvad for dem fremtræder problematisk. Bevægelsen mellem forskellige steder synliggør hverdagspraksisser og situationelle forskelle i kraft af kontrasterne mellem stederne.

I klinikkerne relaterer læger og patienter ofte til helbredstilstandene gennem målinger, tal og grafer. Der er ikke tale om, at lægen afdækker kroppens tilstand, men snarere at genstanden for medicinsk praksis omhyggeligt produceres gennem samarbejde. Dette kræver aktiv deltagelse fra patienten, som stiller sin krop til rådighed for medicinske undersøgelser. Det kræver ligeledes arbejde fra lægen, der med omhu selekterer og producerer data om kroppen og dermed producerer en helbredstilstand, som er relevant for hans eller hendes fag. Selvom resultater fra medicinske test og undersøgelser ofte behandles som sandfærdige svar på forudgående tvivlsspørgsmål, observerer jeg, at audiogrammer og blodsukkermålinger ligeså ofte giver anledning til nye spørgsmål. De lægevidenskabelige målinger bliver meningsfulde, når de relateres til patienternes fortællinger om deres erfaring med kroppen. Måleresultater og patientens oplevelser udfoldes i relation til hinanden: patientens fortælling stiller visse forklaring til rådighed for testresultatet, mens disse leder udforskning af patients erfaring og hverdagsvaner i en bestemt retning. I processen bliver hverdagens vaner transformeret til 'livsstil' i relation til diabetes, mens de bliver til 'livsvilkår' i relation til hørenedsættelse. Fra konsultationerne lærer vi at patienterne tilskrives væsentligt forskellig epistemisk autoritet. En patient med hørenedsættelse tillægges autoritet til at vurdere tilstanden af sin hørelsens, og bedømmelse spiller en afgørende rolle for hvordan hørenedsættelse sammensættes i klinikken. En patient med diabetes derimod tilskrives ringe autoritet til at bedømme sin helbredstilstand; oplevelsen af velvære ikke tillægges samme betydning, fordi høje blodsukre ikke altid er ledsaget af mærkbare symptomer. Dette er blot en af de forskelle, som fremtræder af sammenligningen mellem de to sygdomsområder.

I hjemmene håndteres hørenedsættelse og diabetes naturligvis helt anderledes. I modsætning til klinikkerne, hvor læger og patienter er dedikerede til undersøgelsen af helbredstilstandene, har begge helbredstilstande en mere utydelig fremtræden i hjemmet. Hørenedsættelse kan forårsage problemer i situationer med støj, hvor det er svært at holde en samtale i gang, men i mange andre situationer, når man er alene eller i stille omgivelser kan tilstanden være helt fraværende. Ligeledes kan diabetes være stort set ubemærket i de tidlige stadier og når den er velreguleret. Min undersøgelse af hverdagslivet med hørenedsættelse eller diabetes tager sit afsæt i denne umiddelbare mangel på synlighed, som var problematisk for flere af de mennesker jeg mødte. Jeg viser, hvordan hørenedsættelse fremstår relationelt; den optræder i relation til specifikke omstændigheder, rum, lyde og andres høreevner. Den håndteres ved at rykke sig nærmere, være særligt opmærksom og undgå steder med larm eller mange mennesker. Den forandres af, men forandrer samtidig også situationen man befinder sig i. Håndteringen af diabetes er nært relateret til målinger, som fortæller om tilstanden er i kontrol. Men måleinstrumenter gør mere end blot at måle. De gør folk i stand til at vinde kontrol, til at oversætte en abstrakt og fjern helbredsrisiko til konkrete og kortsigtede mål og til at skabe enkelhed i en overvældende og kompleks mængde af information om diabetes. Det betyder dog ikke at sygdommens uforudsigelighed ophører, da komplikationer kan opstå pludseligt og uventet. De mennesker jeg mødte, som havde diabetes, eksperimenterede med forskellige måder at håndtere deres helbredstilstand og bearbejde det påbud om sund levevis, som gennemsyrer behandlingsområdet, så det ikke koloniserede deres hverdagsliv. Fra et situeret engagement, påtog mine informanter sig at vurdere, bearbejde, håndtere og foregribe deres helbredstilstande.

Diabetes og hørenedsættelse medieres af de teknologier, der er designede til at behandle dem. Helbredsproblemer bliver ikke blot afdækket, diagnosticeret og så behandlet. En sådan linearitet af hændelser indebærer en antagelse om, at sygdomsproblemer forekommer uafhængigt af behandlingsmuligheder, og maskerer dermed sammenviklingen af sygdomsproblemer og deres løsninger. Med begrebet konfiguration, analyserer jeg behandlingsteknologierne som materialiserede figurationer, der påvirker konkrete meningsfulde relationer mellem personer og objekter. Med dette analytiske greb, observerer jeg, at hørenedsættelse i relation til høreapparatet figurer som en sansmæssig funktionsnedsættelse der kan behandles ved at forstærke lyde udefra ind i øregangen. Denne løsning fremhæver den fysiske funktionsnedsættelse af den individuelle krop, i modsætning til den relationelle karakter af hørenedsættelse, som fremstår med hverdagslivets praktiske imødekommen af nedbrud i samtaler. I relation til insulininjektioner, figurerer diabetes som en tilstand af forhøjet blodsukkerniveau, der kan sænkes med medicin.

Denne løsning fremhæver betydningen af blodsukkerværdier i diabetes behandlingen og peger samtidig på én enkelt metode til at bringe disse værdier ned på et normalt niveau. De står i modsætning både til andre metoder at holde blodsukkeret indenfor normalområdet og til andre aspekter af diabetes behandlingen. Teknologiens indflydelse på helbredsproblemet betyder dog ikke, at de determinerer bestemte figurationer af helbredstilstandene; præfikset *kon-* minder os om at teknologi er figureret *med* mennesker. Jeg argumenterer derfor for at helbredstilstandene opstår i relationer mellem personer, måleapparater og behandlingsteknologier.

I de to virksomheder, præsenterede vi et udpluk af vores etnografiske materiale, analytiske tanker og design koncepter på en udstilling, som spurgte sine besøgende 'Skaber vi problemer eller løsninger?'. Formålet var at artikulere de antagelser, som ligger til grund for design af høreapparater og insulinpenne, og at starte diskussioner om relationen mellem sygdomsproblemer og deres medicinsk teknologiske løsninger. En antagelse, som fremstod tydeligt i samtaler mellem medarbejderne under udstillingen, var at patienter har brug for at erkende alvoren af deres helbredstilstand, så de kan starte behandling i tide. Motivation fremstod som et centralt begreb i medarbejdernes billede af patienterne, og frygten for at blive stigmatiseret som bruger af høreapparat eller insulin blev brugt til at forklare hvorfor nogle mennesker udskyder behandlingsstarten. I forlængelse heraf, blev det betragtet som de sundhedsprofesionelles rolle at uddanne, imødekomme og støtte deres patienter i at opnå en passende forståelse af deres helbredstilstand og blive klar til behandlingsstart. Disse antagelser resonerer med den model, jeg har kaldt 'barrierer til behandling'. Men, antagelserne var også genstand for diskussion og overvejelser. Den fremtrædende rolle, som målinger og medicinsk dokumentation ofte tillægges blev diskuteret, ligesom antagelserne bag design af høreapparater og insulinpenne blev taget op til debat. For eksempel blev det foreslået, at hørenedsættelse ikke kun skal betragtes ud fra individets oplevelse, men også fra andre familiemedlemmers perspektiver. Andre deltagere bemærkede at numeriske figurer kan være vanskelige for patienter at omsætte til handling, og de diskuterede derfor andre måder hvorpå de kunne relatere til diabetes. Deres situerede genfortolkninger gjorde det tydeligt, at 'barrierer til behandling' ikke gjorde fyldest til den diversitet i forståelser af brugere, der var på spil i virksomhederne.

Når vi retter opmærksomheden på den praktiske bedrift det indebærer, at gøre behandling relevant, åbner det for en analyse på tværs af materielle og sociale relationer. Det rejser spørgsmål om, hvordan personer i interaktion med hinanden meningsfuldt relaterer til målinger, helbredstilstande og behandlingsteknologier. Det indebærer, at der ikke er en lineær bevægelse – med barrierer på vejen – fra afsløring af helbredstilstande til påbegyndelse af behandling. Behandlelige helbredstilstande fremkommer af situerede praksisser, og undersøgelser af helbredsproblemer er uløseligt forbundet til behandlingsmuligheder.